Multiple myeloma: The patient's perspective

by **Donnaleen Vlossak and Margaret I. Fitch**

Abstract

Multiple myeloma is an incurable malignancy that accounts for 1% of all new cancers, usually affecting older patients. It follows a variable and unpredictable course. Despite years of research, outcomes remain poor.

The purpose of this qualitative study was to gain an understanding of the impact of multiple myeloma on the patient and family. Based on 20 in-depth telephone interviews, several themes were identified and analyzed.

The results were surprising in that every patient interviewed considered the suddenness of having to face his mortality the most difficult obstacle to overcome. While specialized physical care will always be very important, the time has come for nurses to listen more carefully to the psychosocial concerns of this group.

Introduction

Approximately 2,000 Canadians are diagnosed each year with multiple myeloma (Nizar, Bahlis & Stewart, 2006). Most are over 50 years of age, but 10% to 15% will be in their 40s or younger (Corso, 1998). Median survival with conventional chemotherapy is three years. Autologous stem cell transplant can offer an extra year. (Nizar, Bahlis & Stewart, 2006).

Because the disease is relatively unknown to the general population, and the prognosis is so grave, the newly diagnosed patient and family members face many terrifying unknowns: What is the nature of this disease? Can it be cured? What will the treatments be like? Will I be able to do it? What will the future have in store for us?

The person who is diagnosed with the disease faces issues surrounding long-term treatment including chemotherapy, radiation, possible stem-cell transplant, monthly bisphosphonate therapy and, occasionally, other expensive supportive medications, such as erythropoietin and antibiotics (Barrick & Mitchell, 2001). All the while the person is realizing that this is just an interim measure to perhaps provide some disease control for an indefinite period. The patient is reminded daily of the changes in lifestyle, whether due to pain, or fatigue, or possible disfigurement from multiple fractures (Rice & Sheridan, 2001). Everyday activities can be curtailed by loss of independence and frequent hospital visits.

The diagnosis of cancer affects the entire family (Kristjanson & Ashcroft, 1994) and multiple myeloma is no exception. Other family members may have to "take over" the roles of the ill member, often resulting in increased strain on family relationships. As health care professionals, we cannot presume to know what it is to live with a diagnosis of cancer as complex as multiple myeloma. In order to better respond to the needs of the patient and family, the nurse first needs to understand the impact of the disease from their perspective. What is required is a body of knowledge describing this impact drawn from patients' experiences living with this illness.

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Background

To date, very little literature is available describing the impact of multiple myeloma from the patient's point of view. Patients with breast, lung, and ovarian cancers, among others, have been studied over the years, and the literature points to the fears, frustrations, and lifestyle changes these patients experience, as well as the changes in family dynamics that accompany such a diagnosis. Although some of the data gleaned from these articles can be transferred to the patient with multiple myeloma, the major difference is that the patient with multiple myeloma knows from the very start of the illness experience that this is, indeed, an incurable disease with a short-term survival period. Optimism for a cure is not an option.

Rice and Sheridan (2001) discussed the nursing care of patients with multiple myeloma as a paradigm for those populations that are underserved. Because the incidence of multiple myeloma is higher in the elderly and the Afro-American populations, the authors argue that nurses should pay special attention to the unique physical and social needs of these groups. They cited needs such as chronic pain, depression, and other co-morbidities, complicated by limited financial resources and lack of medical coverage.

Santos, Kozasa, Charffailleb, Colleoni, & Leite (2006) studied the prevalence of post-traumatic stress disorder in a group of patients with hematological malignancies in Brazil. The researchers found patients with multiple myeloma had the lowest quality-of-life scores in the physical functioning subscale. As well, anxiety and depression correlated positively with symptoms of pain, insomnia, and fatigue.

In a study of patients with multiple myeloma exploring pain, mood disturbances, and quality of life, subjects reported higher levels of mood disturbance than patients with other cancers in other studies (Poulos, Gertz, Ponkratz, & Post-White, 2001).

There is a dearth of evidence about how the patient with multiple myeloma perceives his illness, how he copes with it, how he makes decisions regarding treatment, what the impact is on his finances and family, and how multiple myeloma may have changed his hopes for the future.

Purpose

The purpose of this study was to explore, in a qualitative manner, the impact of a diagnosis of multiple myeloma on the patient and family. The researchers looked at the patients' experiences, trying to identify perspectives specific to living with multiple myeloma. Identification of common themes could help inform practice approaches for this patient population.

Methods

Multiple Myeloma is a complex malignancy of the plasma cell that accounts for about 1% of all cancers and for 2% of all cancer deaths (Multiple Myeloma Research Foundation, 2008). It is more common in men than women, with more than double the incidence in those populations of African descent compared with Caucasians. While the disease is occasionally diagnosed on a routine physical examination, it is more commonly discovered when the patient presents with fatigue, recurrent infections, weight loss, and anemia. Often, severe symptoms such as pain, as a result of bony lesions, renal failure, or even fractures can be the first indication of the disease. Diagnosis is confirmed by the presence of high levels of plasma cells in the bone marrow, and abnormal paraprotein levels in the peripheral blood. Skeletal surveys

often show asymptomatic lytic lesions in the bones, with elevated serum calcium levels. Twenty-four-hour urine specimens are usually positive for Bence Jones protein. Treatment, mainly steroid based, is aimed at reducing the abnormal protein from the blood, thereby improving such side effects as anemia and renal function. Younger patients receive high-dose steroids and chemotherapy, followed by autologous stem cell transplant. Radiation is helpful in improving pain and mobility issues. Other supportive measures such as erythropoietin and bisphosphonates, and analgesia can also be employed. Many patients take part in clinical trials in the hope that they will benefit from some new regimen.

This qualitative study was conducted with a convenience sample generated from the list of patients receiving treatment from two hematologists in a large regional cancer centre in Ontario. The patients were approached in an outpatient clinic by the researcher regarding whether or not they were interested in learning about a study examining the impact of their diagnosis on their lifestyles. The ability to speak English was a necessary prerequisite. Interested patients were then contacted by telephone by an interviewer who explained the study participation to them. A consent form was then sent to the interested patient and an interview arranged if they agreed to participate.

Consenting participants were asked open-ended questions to allow them to discuss what was important to them. The interview questions included demographic items (age at diagnosis, length of time since diagnosis, occupation), personal experiences during the diagnosis and treatment, the impact the disease and its treatment has had on the patient and his family, and how this disease may have changed their hopes for the future. These in-depth interviews were conducted by telephone, except in one case, which was a face-to-face interview in the chemotherapy unit. The interviews lasted between 30 and 90 minutes.

The interviews were transcribed verbatim and any identifying features removed from the text. The transcripts were subjected to a standard content and theme analysis (Silverman, 2000). The investigators read through the transcripts independently and made marginal notes about the content. The investigators then compared their notations, discussed their perspectives about the data, and agreed upon a content categorization scheme. All the content in the transcripts was then coded according to this agreed-upon categorization scheme. The content analysis focused on decision-making; the amount of information available about the disease and treatments; coping mechanisms; emotional, physical, social, and financial impacts; relationships with family and friends; side effects of medications; and changes in their hopes for the future. Each coded category was reviewed by the team and key ideas identified. These key ideas became the themes. The themes reflect the emphasis the participants placed on key ideas during the interviews. For this reason, this article will concentrate on the psychosocial issues.

Findings

Twenty patients were interviewed, ranging in age from 44 to 88 years of age. There were 13 males and 7 females. Time since diagnosis ranged between six months and six years. Patients were assigned a unique identifying number that is indicated at the end of each quote.

Theme 1: The diagnosis was shocking and unexpected

Without exception, the participants expressed surprise and disbelief at the time of diagnosis. Most had never heard about multiple myeloma. Those who are computer literate looked it up online and were shocked by the negative information that was presented. The thought that it was an incurable disease with a short life expectancy and very few options for treatment was almost too much to bear. Life had changed irrevocably with little warning.

It was described on various sites as incurable...only palliative care to look forward to, and that was frightening. And the idea was...kind of final. (12)

I went to the library and read a book, one of the reference books. It more or less gave me two years. And that just freaked me right out. That made a basket case out of me. (14)

Some patients had been visiting their family doctors for many months with symptoms of chronic pain, frequent infections, or even fractures before a definitive diagnosis was finally made. Most had not entertained the idea they might have cancer.

I had back problems since I was a teenager...it really didn't go away...I went to a chiropractor...I was still getting pain. I played my last game of hockey in November...By January, I couldn't lift my feet up off the bed...I went to paralysis...and then they found a tumour in the spine. The biopsy showed that I had cancer. (13)

I had a lot of pain...for two years they kept telling me I had fibromyalgia...the pain was not going away. It was terrible, the constant pain. Then, finally, my doctor had me see a specialist and they discovered the cancer. (4)

Theme 2: There are few options for treatment

Patients expressed surprise that the same induction chemotherapy regimens have been used for more than 25 years. Treatment often commences immediately after diagnosis in order to control symptoms, so the patients found they had little time to weigh any options that may have been offered. Autologous stem cell transplant is a possibility for those younger patients under age 65 (Imrie, 2002). Because the majority of newly diagnosed patients are over the age of 65, other family members' health issues also had to be taken into consideration before a treatment decision could be made (Fitch, 2005). For example, those who were the primary caregivers did not feel the family could sustain the long hospitalization required post-transplant without them. Others felt they had enjoyed good health in the past, as well as a long satisfying life and, therefore, opted for a more palliative approach. They preferred a "quality of life" approach.

Table One. Patient demographics

Patient ID#	Age	Gender	Length of Time Since Diagnosis
1	61	F	4 years
2	69	M	1 year
3	69	M	2 ½ years
4	69	F	(not stated)
5	69	M	1 year
6	88	F	10 months
7	68	M	1 year
8	73	M	6 years
9	73	F	5 years
10	50	M	1 year
11	48	M	18 months
12	50	M	3 years
13	60	M	2 years
14	49	F	1 year
15	60	M	4 years
16	69	F	4 years
17	72	M	6 years
18	62	M	1 year
19	67	F	5 years
20	69	M	1 year

I made that (decision) right there and then. I wasn't prepared to be sitting in the hospital, going through all of that... My wife had a stroke, just about a year ago, just before Christmas... I don't know about the stem cell... It just didn't fit my purposes at the time. (3)

Well they explained to me the fact that there was the chemo option and there was the transplant option... I feel I've done enough... I don't think that at this point in my life I'm going to go through that kind of stuff. (20)

On the other hand, the younger patients (those under 65) definitely wished for the most aggressive treatment possible. They and their family felt the best option for control of the disease was offered by high-dose chemotherapy followed by an autologous stem-cell transplant.

The doctors told me that this is what they recommended... I had no reason to question what they were doing and so, therefore, this (transplant) seemed to be fairly standard treatment, so I went along with it. (10)

It's all much more cut and dry than I even thought. So, when you're talking about options and everything else, you realize there aren't really any. You either get a transplant or you don't. (2)

It is noteworthy that once a treatment plan had been decided upon, all the patients interviewed stayed the course, rationalizing that the decision taken had been the correct one for them.

Theme 3: Worry about the family and how they will handle the diagnosis.

The function of the family is thrown into disarray when one member is faced with a life-threatening illness (Marcus Lewis, 2005.) The demands of the illness can intrude upon the integrity of the family, which, in turn, can interfere with each member's life. This is a time of psychosocial transition in which the members attempt to balance life as a family with life as a family with cancer.

Feelings of inadequacy in carrying out usual tasks whether or not it was within the home environment or at work were evident in most of the interviews.

I went from travelling around the world and managing 500 people to making lunches for my family. That was about the only useful thing I could do in the day. (11)

The feeling of being a burden to family and friends was expressed. Ambiguous feelings of resentment, guilt, and uselessness were particularly evident among the female patients.

Well you look at yourself. You are not the one you used to be for your children, for your neighbours. (5)

We argue a lot because, I guess, I feel guilty often... sometimes I resent the fact that there he is playing golf and I am stuck here. You do get those feelings no matter. You know it's wrong... (4)

I really feel, in my heart, that it (multiple myeloma) made a difference. And it is making a difference... That he (husband) just doesn't want to be seen with me... almost... (14)

Responsibility for informational needs, appointments and treatment dates and records is frequently assigned to another member of the family, usually the patient's wife. This person attends every appointment, sits at the bedside during the long hospital stay, and often becomes the main decision-maker.

My wife understands a lot more... she's a lot more involved with it. I just let her do everything. I put myself in her hands, and the hospital's hands, and knew that everything would be OK. (7)

She has been there every doctor's appointment. She was there every day when I was in the hospital for the transplant. We talk a lot more about what is going to happen. (10)

It's getting too hard for her to be looking after everything... she's trying to be the lady of the house, the caregiver, the wife, the goal person, the shopper... to do everything here. (3)

In other cases, the struggle to cope with a partner's illness is so difficult that the way the spouse copes is by avoiding the situation altogether.

My husband absolutely hates hospitals and doctors... My youngest son has been the one that's been the best... he comes with me a lot to the appointments and stuff... he (husband) doesn't bother with it because he doesn't understand. (19)

Patients with younger children seemed to have great difficulty addressing the gravity of the disease with the youngest members of the family.

I have not pushed them (daughters) into reality... I haven't sat down and said, "So, since this is happening, this is going to happen". Because I just can't do it yet. I have to. To be fair to them, but I haven't yet. (14)

Older children such as teenagers are dealing with their own developmental tasks, and the issue of a parent with a life-threatening condition can be more than they are capable of handling. Their way of dealing with this threat to the family may be avoidance.

I've teenagers and teenagers are pretty self-centred even though they are sympathetic and supportive, they almost immediately go back to their own lives. Like, they really don't get it. (11)

You can't do anything with the kids. Like you know, the 12-year-old really doesn't understand, because she says, "What are we doing tonight because Mom's home now?" (14)

Theme 4: Treatment is difficult, long, and very complex

Patients and their families quickly become "experts" in treatment modalities for this disease. They soon learn the frequency of the chemotherapy cycles, the side effects of the steroids, and the significance of laboratory values. Chemotherapy can range from oral steroid-based medications to high-dose chemotherapy with autologous stem cell transplantation. Monthly clinic visits for bisphosphonates, expensive parking fees, and boredom during long weeks in hospital after the transplant were all cited as adding to the patient's stress. Some worried about laboratory results that may signal the beginning of the end.

Radiation is one of the standard treatments in controlling pain from boney lesions and may be delivered several times throughout the disease trajectory. As well, at some time during their illness, patients usually will require analgesia, generally in the form of narcotics to help alleviate pain. Steroids, which are the main chemotherapy drug, come with their own set of side effects, the most troublesome being mood swings and emotional volatility, further increasing stress on the family. Other treatments, such as those of the Thalidomide classification, cause fatigue, lethargy, and severe constipation. In most cases, the patient and the family felt that they had no choice but to cope with the situations as a result of the treatments.

You are on morphine so you are kind of whacked out and tired most of the time... so you are sort of stuck at home. I couldn't drive. (11)

You survive it. You put up with it. (2)

The greatest medicine you get to deal with is in between your ears. So, if you make that work, then that works. And if you don't, you can have a rough ride. (13)

Theme 5: Fatigue can be overwhelming

Fatigue is one of the most common complaints among patients with multiple myeloma. One gentleman was very eloquent in his description of fatigue.

From cancer you are tired, but you are inner tired, and when you lie down, you feel the tiredness sink into the bed... and that is always there. When you walk outside, you feel your shoulders, legs, and hips. So you are forced to slow down and you are forced to go home. (5)

Theme 6: Loss of independence

No matter the age of the patient, one of the strongest feelings surrounded their perceived loss of independence. Whether or not it is being unable to go to work, doing chores around the house, shopping, or socializing with family and friends, they missed their ability to live their lives independently.

I can't manoeuvre my arm properly so I haven't been driving for about a year, which drives me crazy. Losing my independence, that's been my main problem. (1)

It's the illness that has taken over. And I don't like being ill. I've always been quite healthy and have always done things for myself and all of a sudden I'm depending on others. (6)

Entwined with the loss of independence, a common theme of feeling useless was heard in all of the interviews. A highly regarded attribute in Western society, the perception that one's contribution to the family and to society has been usurped by a diagnosis of multiple myeloma can be depressing.

I did the food shopping for my wife from the day we were married. Now she does it... she says she hates it. I can't drive right now. So you're all alone and you think, "What the hell is this all about?" I have nobody unless my wife is home or the kids drop in or something. (7)

I just feel I have no life. (4)

In addition, those patients who were still working had to quit, either permanently, or for some period of time during their treatment. This often led to feelings of boredom, loss of personal identity, and financial hardships.

I felt so bored, I was in bed... I had a fractured vertebrae and some ribs. So, for someone who was always working out, I didn't take too well to not being able to do anything. (7)

I am a busy executive; I am not that old; I am used to doing a lot of things. And so, sort of being stuck at home was really almost more of an impact than anything. (11)

I had to cash in all my RRSPs... I am going to sell my house and I am going to live with my daughters. So what was kind of a good little life has turned out to be something else. (3)

Theme 7: Change in self-concept/self-image

The loss of independence, and not being able to do what used to be routine tasks, as well as having to depend upon others often results in a change in self-image.

That (motherly care) is wonderful, (but) it can sometimes be debilitating because the fact that it weakens your whole being by being looked after when I've always been extremely independent and looked after myself. (20)

(I am) not liking what I am seeing. I don't like being the way I am right now because it doesn't look like me. It doesn't feel like me. It's not what I am really. (4)

You are an old man, because you walk with a stick. (5)

Theme 8: Obsession on how and when the end will come

The realization that one's life is going to be shortened significantly is another common theme that emerged from these interviews. Some patients coped with this by assuming (incorrectly) that they could have indefinite transplants whenever symptoms worsened. Most of the others were realistic and felt they had fewer options once a recurrence occurred. They feared "how" and "when" death would happen, and dreaded the regular blood tests that may signal a recurrence.

People may say that they could get hit by a bus, but we with myeloma know the make of the bus, the name of the bus. You know, sometimes we can even see the licence number of the bus, when we're, you know... out of remission. (16)

So the impact with feeling that you're in disrepair is quite considerable... but you're never 100% and (it's) always on your mind that there's something wrong with the blood. (20)

So, suddenly for the first time somebody's sort of given you a rough map of the rest of your life, you have no idea the length, you don't know how ugly the end's going to be. (17)

Patients cope with living with uncertainty of what the future has in store for them in various ways. Some cling to the hope that normal blood and urine values will provide numerical "proof" that their life will be extended.

It's the not knowing. Then I get good news that "your counts are up, or your counts are down. "Gee, that's wonderful." And then something will come along that's not so wonderful. So you just don't know. It's the same in life. (1)

I call it every two months, the Russian roulette. You get a blood test taken, spin the stuff and see if you have a couple more months to live. (11)

Others are hopeful that new drugs, clinical trials, and possibly another transplant will offer them an extension of their life.

I think about it (end of life). So, at the next visit I said that I didn't want to talk about this dying crap. I want to talk about what we talked about before, the transplant. That if we can buy time, there are lots of new drugs and trials, etc. I want to talk about that. (16)

Other patients maintain a more pragmatic approach to life and, while accepting that life as they now know it may not be long, they hope for as much time as possible.

I just keep thinking positive, and tomorrow's still going to be a while, and let's fight this thing and make it last as long as we can. (18)

You don't (prepare for the possibility of bad news/death). All you can do is just suck it up and go, you know? That's all you can do... and just hope that now is not the time." (17)

However, worries persist, mostly about how the family will manage without them, as well as the thoughts of missing out on major family events.

I want to hurry up and get back to work. Obviously, because it hasn't ruined us, but (it) really is taking a toll... when Mom is not working, it means that we don't do the fun stuff. (14)

My daughter just graduated from public school last week. I wonder whether or not I am going to be around when she graduates from high school... I don't have any pensions; we don't have huge savings. So I think it is more financial concerns for her (wife)... how are the kids going to go to university? (10)

I think about dying, And sometimes it scares me and sometimes it doesn't. I guess it all depends on the mood. But, you know, the thing is I know everybody's going to die. (1)

Theme 9: Fear of recurrence

Coupled with living with uncertainty is not only "when" will the disease recur, but "how" will the physician be able to treat it? Are there any treatments left to control the myeloma?

Now I find if a bone starts to hurt or a joint or something, I have to stop and think, "Well, what have I done? Or is it the myeloma settling in again, in another area?" (19)

My own concern is that, when is this thing going to come back? If it does come back, and they give me the same treatments that they did before, can I still get a stem cell transplant? Can they still do whatever they have to do with my blood? (5)

I just look at the short term, and get through the next step in this process of trying to control the disease... always knowing in the back of your mind in the long term, how long will these things that you're going through, how long will they keep this disease asleep? (18)

Theme 10: Rationalization of changes in their hopes for the future

Hopes for the future vary according to each patient. However, in most cases, the patients admitted they were looking at their goals and perhaps moving forward with at least some of their dreams.

At least I may know when the time is coming compared to others. I hope that some of the goals that I have established to do now, you know. I know exactly that I'm not going to work, that it's time to start doing a little more travelling if I can, and spending time with my family and my grandchildren and so on. (18)

In the case of older patients, many have come to terms, more or less, with the realization that their lives are soon to end. They have examined what they have done in the past, and will live a life as fully as is possible.

And it takes a while to sort of realize that, no... the universe is not going to unfold as you had hoped... we don't have those things in the ads, the golden years where we're off to Tahiti! First of all because the insurance company just looks at you and laughs! (17)

We've fulfilled everything that we wanted to do. We never denied ourselves any vacation. We still go on vacations now. We take each day as it comes, you know. It's as simple as that. (3)

I don't want to waste my time working now. What time I have left, to me, it's much better to think positive and do the things that you want to do rather than be sidetracked by work. Albeit it's nice to have the money, but these are the choices you have to make. (18)

I don't want to focus on the dying even though I'm not stupid... it hangs there, at the back of your mind, in your subconscious. You're never really free of the fact... it's always going to be with you as long as you live. You don't know how long that's going to be." (16)

Discussion

Currently, there is a dearth of literature describing multiple myeloma, particularly its impact on the quality of life of patients and their families. While the multiple myeloma population is small compared with that of other cancer populations, it has its unique issues that impact upon the patient and the family unit.

Multiple myeloma is predominantly a disease of the elderly who, having worked a lifetime and are anticipating retirement and the enjoyment of family and friends, find they are unable to fulfill their dreams. Finances can be depleted rapidly due to expensive treatments such as Velcade and Thalidomide, as well as supportive medications such as erythropoietin, frequently not covered by insurance plans.

Additionally, because multiple myeloma is an abnormality of the plasma cell, all areas of the body can be affected either separately or in combination. Therefore, patients fear how "the end" will come. Will they suffer from painful bone lesions and loss of mobility? Will they require renal dialysis due to loss of kidney function? Will pancytopenias lead to infections, excessive fatigue and hemorrhages creating medical crises with a subsequent decrease in their quality of life? No matter what lifestyle changes they may embrace to help manage their myeloma, there will be virtually no difference in disease progression and medical outcomes.

This was an introductory study of 20 individuals with multiple myeloma. It would be prudent to repeat the investigation with a larger sample in order to validate our findings. As well, a comparison of coping skills between men and women could also prove to be helpful in providing more appropriate nursing care.

Conclusions

Our study has shown that patients with multiple myeloma are accepting of the medical interventions offered. They indicated they are generally satisfied with the physical care they receive. However, in this study, their responses demonstrate that their primary needs are emotional and psychosocial.

When the patients were questioned about sharing these feelings with their physicians and nurses, almost all were reluctant to approach the medical team with concerns surrounding their emotional health.

I have my monthly meeting and they're so busy... you're sort of in and out. I just think because they're so busy I don't feel comfortable doing it right now... you go there and my God, there are a hundred people waiting. So you hate to, you're waiting two and three hours to see them. You don't want to do that to somebody else. (4)

Well, like I say they (medical team) look so busy. And you go in and you see these poor people that are desperately ill and you think, well I don't know what I am complaining about because I can do this and that and the other. So almost, what I am doing here? (16)

It is a universal human reaction to a diagnosis of cancer to experience a myriad of emotions. In most cases, each newly diagnosed cancer patient is presented with a plan that may or may not include surgery to remove a tumour, chemotherapy to destroy the malignant cells, or radiation to "mop up" any remaining microscopic cells, or a combination of all three, all in the hope that the cancer will be cured. And many patients are, in fact, cured. They are willing to put up with all of it for a possible cure. For example, many women with breast cancer go on to live a normal life expectancy. Many of the lymphomas and leukemias are also cured.

However, patients with multiple myeloma do not have this option. They know from the first time they meet with their oncologist that they have a finite life expectancy. The disease can be "controlled" for a number of months to years, even with potentially life-threatening treatments such as stem-cell transplantation, but the bottom line is that the disease will definitely recur, usually within three to five years. How and when this will happen cannot be known, and this seems to be one of the most difficult aspects of living with multiple myeloma for both the patients and their families. The concept of "hope," in this case, is not related to a cure, but rather as hope for a relatively healthy life for as long as possible. In this respect, multiple myeloma does differ from those other diagnoses of cancer that are curable.

It is this uncertainty of a certainty that seems to produce the most anxiety. The monthly blood tests that measure protein levels are a constant source of stress, even if the patient is feeling well. Each new ache or pain is a reminder that the disease may be out of remission and that his life is on a downward slope. "What will happen next?" he wonders. "Is this the beginning of the end?"

As nurses, we have a fundamental role to play as part of the medical team, in all aspects of our care of the patient with multiple myeloma. We can increase our awareness of the depth of emotional pain that these patients, their spouses, and families suffer during this time. We can offer support, as well as refer them to the entire multidisciplinary team as they try to live their lives as normally as possible. In addition, several patients indicated financial concerns, suggesting that social services may need to be involved to address these needs.

It is the hope of the researchers that as you care for your patients with multiple myeloma, whether it is delivering their chemotherapy, dealing with the side effects related to treatment, or assisting them with their pain medications, all along the disease trajectory, you will have an increased respect for the emotional implications of living with this grave disease.

The biggest problem is probably the emotional problem and that's more about the uncertainty about the future and, to be honest with you, that has been the biggest obstacle as opposed to any physical problems of the process of treatment itself. (10)

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