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Managing relapsed myeloma: the views of patients, nurses and doctors.

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**Aim:** The study aim was to explore whether there were differing opinions on the current management of relapsed myeloma between patients and health care professionals, a topic which has never been explored previously in the literature.

**Method and Sample:** This qualitative study was undertaken at a regional specialist haematology centre in Ireland. Individual interviews were undertaken with multiple myeloma patients with relapsed disease (n=8). Three focus groups were also undertaken with haematology nurse specialists, haematology doctors and staff nurses working in a haematology day unit (n=17). The analysis of interview data was guided by thematic analysis.

**Results:** Two central themes were interpreted from the interview data: 'shared decision making with the expert patient' and 'an unpredictable disease journey'. Patients felt they were well informed regarding their illness but faced difficult decisions at times. Nurses and doctors stressed the importance of the early introduction of palliative care but acknowledged difficulties due to myeloma being unpredictable.

**Conclusion:** Managing relapsed myeloma was fraught with complex issues. Patients developed alternative ways of coping with their disease including adopting the role of the 'expert patient', continuing to battle their disease and living with a chronic illness. Health care professionals struggle to manage the realities of a disease where the prognosis is improving. Uncertainty around patients' care and difficulties such as when 'enough is enough', continue to cause challenges. The transition to a chronic disease offers hope to myeloma patients and an opportunity for health care professionals to implement holistic care plans which encourage patients to be proactive in their care.

Key words: Myeloma, Qualitative, Relapsed, Nurses, Doctors, Patients.
Introduction

Myeloma (also referred to as Multiple Myeloma) is a blood cancer characterised by uncontrolled plasma cell proliferation (Palumbo et al., 2011). This cancer leads to a variety of symptoms, including bone pain, fatigue, hypercalcemia, renal insufficiency and reduced blood counts leading to anaemia, infection and the increased possibility of bleeding (Coleman et al., 2011). It is a very individual cancer, both in terms of what symptoms and complications patients experience and how they respond to treatment.

Myeloma is relapsing-remitting in nature. This result in periods when the disease is causing symptoms that require treatment, followed by periods of stable disease where treatment is not required (Myeloma UK, 2015). Patients with relapsed or refractory disease are defined as those who, having achieved minor response or better, relapse and then progress while on salvage therapy or experience progression within 60 days of their last therapy (Richardson et al., 2007). With the introduction of novel treatment agents, myeloma patients are now living longer but must learn to manage the risks associated with the illness and its treatments, such as infection (Stephens et al., 2014). New and targeted therapies has resulted in a substantial impact on the lives of patients with relapsed myeloma and has improved treatment outcomes as well as prognostic factors for patients (Dimopoulous et al., 2011). Treatment options currently available for relapsed myeloma patients include the use of targeted therapies such as lenalidomide and bortezomib. For patients who have become resistant to the majority of treatments, a clinical trial is an option which may include the use of carfilzomib (Dimopolous et al., 2011).

The improved survival of patients with myeloma has resulted in an increasing symptom burden not only due to the disease but also as a result of the cumulative effects of treatments (Snowden et al., 2011). In addition, it has been suggested that oncology patients’ needs are inadequately met by the health care system (Lobb et al., 2009). There is little known about myeloma patients’ care needs and the importance of supportive care in their outcomes (Molassiotis et al., 2011b). Supportive care has been described as care that assists a patient and their family to manage a diagnosis of cancer from pre diagnosis until death and after. Research has shown that unmet care needs results in higher levels of anxiety and depression and patients with multiple myeloma have higher levels of symptoms and problems compared to any other haematological cancers (Molassiotis et al., 2011a; Johnsen et al., 2009).

The aims of this study were to identify if the care needs of relapsed myeloma patients are being adequately addressed and explore if there are differences in perspectives about patients’ care needs from both patient and health care professional point of view.
**Background**

In comparison to those with lymphoma and leukaemia, myeloma patients generally report more issues and distress which may result from bone pain, bone fractures and recurrent infections (Johnsen et al., 2009). The most severe symptoms in this population are fatigue, pain and insomnia (Johnsen et al., 2009). Side effects of treatments have been reported as the single most important predictors of unmet needs highlighting the importance of proactively managing common symptoms and side effects, especially those as a result of long-term treatment (Molassiotis et al., 2011a).

Other unmet needs identified in a cross sectional survey of myeloma patients conducted by Molassiotis et al. (2011a) includes accessibility to hospital and concerns about the return of myeloma. Haematology patients raised concerns about the lack of information about side effects of medications, and similarly McGrath and Patton (2010) identified that education and support are often neglected. Patients have identified areas of their care which could improve and thus reduce anxiety, depression and increase quality of life. Lobb et al., (2009) reported that patients with haematological malignancies found it helpful to talk with health care professionals about their diagnosis and treatment, although there is often a lack of continuity of care. In addition, it was identified that social support was a significant support factor in patients’ psychosocial wellbeing with patients often relying on family and friends for support. Furthermore, patients have reported being unaware of support services available, especially emotional support (McGrath, 2000).

Another major concern raised in the literature is the focus on the curative system with escalating technology in dominance until the dying trajectory. Family members also emphasise that the main focus is on quantity of life rather than quality of life (Howell et al., 2010; McGrath, 2002; McGrath and Holewa, 2006; McGrath 2014). It has also been highlighted that patients are given false signs of hope and a lack of honesty regarding dying by their physicians. Clinicians were criticised for continuing to treat advanced disease that is unlikely to respond to treatment rather than transitioning to palliative care when end of life is eminent (Howell et al., 2013). The treatment approach with curative intent results in over medicalisation and inappropriate therapeutic aggressiveness in the last days of life. Timely referrals of patients to palliative care ensures a quality of life for relapsed patients and can control symptoms that may complicate the final course of the disease trajectory (Niscola et al., 2013). Further emphasis should be placed on developing evidence to guide patients and clinicians in treatment decisions that could lead to early and efficient planning of the care needs of these patients (Howell et al., 2010).

Literature has mainly focused on treatment options for newly diagnosed myeloma with the intent of remission. While a number of other studies have focused on haematological malignancies, most are not specifically focused on relapsed myeloma. McGrath (2006) explored nursing insights on end of life care however there is no specific study that focuses on patients with relapsed myeloma and
perspectives from health care professionals involved in their care. This study is therefore timely in view of this current gap in the literature.

**Methodology**

Descriptive qualitative was considered the most appropriate choice for this study as the aim was to explore and describe the unique experiences of individuals living with relapsed multiple myeloma and the views of healthcare professionals managing their care.

Generic qualitative research seeks to understand how people interpret, construct or make meaning from their world and experiences. Qualitative descriptive studies are particularly appropriate when trying to obtain a broad insight into the phenomenon being described and data is generally collected via semi structured interviews or focus groups (Kahlke, 2014).

This qualitative study was undertaken at a specialist regional centre for oncology and haematology in Ireland. Data was collected using individual interviews with relapsed myeloma patients (n=8) and focus group interviews (n=3) with specialist nurses and doctors (n=17).

The sampling was purposive. Patients with a diagnosis of relapsed multiple myeloma (i.e. had received at least one previous treatment) and the ability to give informed consent were invited to participate through an advertisement displayed in the clinical area of the outpatients department. Newly diagnosed patients were excluded as the aim was to explore the experience of patients with relapsed disease which would not be captured in a population with a recent diagnosis. Patients were also informed about the study by the haematology consultants during consultations. Eight referrals from the haematologists were received, five of whom agreed to participate. The reason for non-participation included further disease progression; other life circumstances and one patient passed away. Four patients made contact expressing interest in being interviewed as a result of the advertisement, three of whom agreed to participate; the fourth person did not meet the inclusion criteria due to being newly diagnosed. Six men and two women, ranging in age from 55-85 years and all white Caucasian, were interviewed. Interviews were held in a private conference room within the oncology outpatient department in the specialist centre. The interviews were conducted using open ended questions aided by an interview guide containing five initial questions which focused on patients’ experience of care and treatment.

All of the consultant haematologists working at the centre (n= 4) and two specialist registrars participated in the doctor focus group. Doctors had to be at a minimum a registrar and have specialised in the area of haematology in order to ensure that they had sufficient clinical experience to provide an informed perspective on managing the care of relapsed myeloma patients. Two specialist registrars were unavailable on the day the focus group was held. The second focus group consisted
of nurses (n=6) working in the oncology haematology day unit and all were experienced in the care of relapsed myeloma patients. The nurse participants in the third focus group were all specialists in haematology (Clinical nurse specialists and one advanced nurse practitioner in haematology) (n=5).

The interview guide for the focus groups focused on the nurses’ and doctors’ experience of delivering care and treatment for relapsed myeloma. The questions used in all interview settings focused mainly on the exploration of current care, how it could be improved, the role of palliative care and decision making (Appendix 1).

All individual patient interviews and focus groups were audio taped and transcribed verbatim. Interviews were on average 30 minutes in length.

Thematic analysis (Braun and Clarke, 2006) was used to guide data analysis. The data was analysed across both patient and health professional interviews. Thematic analysis is a method for identifying, analysing and reporting themes within the data. Common themes were identified through the generation of initial codes. Codes that were identified from across all data sets were established via the use of key words, word repetitions and through comparing and contrasting the data sets. Logical relationships were sourced between the viewpoints of both patients and health care professionals. Themes were then formulated as a result of using a thematic map.

Ethical approval for the study was granted by the regional health service ethics committee. A distress protocol was put in place for the study should any patient require support. No patient expressed distress during the study.

Findings

Two main themes emerged however there were also sub themes within these two themes. Sub themes are essentially themes within a theme.

The two main themes were: ‘Shared decision making with the expert patient’ and ‘an unpredictable disease journey’.

A key category within the shared decision making partnership was “The Expert Patient” which emphasised the more proactive role of patients and their good level of knowledge about their disease and its management.

The unpredictable disease journey explored key subthemes such as the “incurable disease”, “the individual journey” and “finding comfort”; all which emphasise the erratic journey that a diagnosis of relapsed myeloma can bring.
Shared decision making with the expert patient

Informed patients, who were considered knowledgeable about their diagnosis and treatment, were of major significance to doctors. Doctors felt that informed patients became more involved in the decision making aspects of their treatment and were fully aware of the consequences of treatment options. Doctors welcomed shared decision-making with patients, as it relieved them of some of the pressure when making difficult decisions regarding treatment options.

“The more informed the patient is the more they are involved in the decision making the better... it relieves you of any guilt than if subsequently things don’t do well or don’t go well...” (FG1, P5, Haematology Doctor).

The specialist haematology nurses agreed, and in particular, strongly emphasised the need for patients to have a role in decision-making.

“My two things would be that they have support and that it is their decision rather than our decision that they have further treatment.” (FG3, P1, Specialist Nurse).

Shared decision making was of equal importance to patients. Patients wanted to be a part of the process. Patients expressed a desire to take on an active role in their management. They often sought out further information about their disease from other sources such as internet searches.

“I would say they [Doctors and Nurses] could give more information on the disease and on the blood tests and blood tests results. I would like to know the numbers on it because I go by the numbers” [Referring to blood results].” (P1 Patient diagnosed for 8 years).

The majority of patients felt that further treatment options were always suggested and they felt that the decision was left primarily up to them. However, there was a belief that the doctors’ advice was in the patient’s best interest. There was a huge emphasis on trusting in the doctors which reduced anxiety among the patients.

“I wouldn’t disagree with the bosses [doctors] they are looking after me and probably the reason why I am here today.” (P2, Patient diagnosed for 10 years).

Doctors also felt that despite the importance of shared decision making, some patients still expected the decision making to fall solely with the consultant.

“... you can ask them well you know what do you want to do and you try to give them all the options and at the end of the day they will turn around say well you know you’re the doctor you know you tell me what to do...” (FG1, P5, Haematologist).
This is challenging for doctors who are often relying on their own judgment when making treatment decisions while simultaneously not wanting to appear as though they were coercing patients. In addition to this they were concerned about their ability to provide enough time for discussions on treatment with patients during busy clinic sessions.

“I am not sure we do that as well as we might and again it’s down to the pressures that we work under and you know the environment.” (FG1, P5, Haematology Doctor).

Nurses felt that patients were greatly influenced by their consultants as a result of the trust placed in them. Nevertheless, the nurses also acknowledged the difficulty doctors faced when making decisions about continuing treatment.

“I suppose medically [continuing treatment] it’s probably the best thing to do so it’s hard to advise them [patients] against it.” (FG3, P5, Specialist nurse).

For patients with limited treatment options, the consideration of a clinical trial was a major decision. All available treatment options were considered and often it involved doctors justifying to themselves another treatment.

“You are in a position to make a decision ... you would feel empowered and you justify to yourself that it is the right decision for the patient.” (FG1, P2, Haematologist).

The decision for a clinical trial and further treatment was not considered lightly and the doctors stressed that the best interests of the patient were always at the centre of their decision-making. However, doctors found it difficult when treatments failed and they expressed the need for caution with patients to avoid raising false hope. Nevertheless, despite these difficulties, a strong sense of satisfaction was felt when a patient did well. One consultant described the experience of a patient who had undergone all standard treatments and his only remaining option was a phase 1 clinical trial.

“This particular patient had gone through all the standard treatments had no other choice and was willing to basically say I am going to call it a day. He went on a trial and now is what 3 and half years on without any problem and has an absolutely good quality of life so when it works it does work.” (FG1, P2, Haematologist).

Some of the patients whose disease had ceased responding to standard therapies were open to “trying anything” and when it came to decision making there was a particular significance placed on not having any other option available to them.

“...they [Doctors] explained everything to me and it was up to myself whether I went on it [clinical trial] or not but I didn’t want to die and that was it and I am doing very well on it you know. I am quite happy. Only for it, I wouldn’t be here today.” (P6, Patient on a clinical trial).
Nevertheless, despite all the decisions reached regarding further treatments, the doctors were keen to highlight that myeloma was incurable and patients would eventually succumb to refractory disease.

“They [patients] are basically going to die from it because once somebody has refractory disease no matter what we do we are just looking at prolonging their life a bit.” (FG1, P5, Haematologist).

Health care professionals explore the many treatment options available. Patients want to continue living and are willing to partake in the shared decision making partnership, however they still depend on the doctors’ influence for some decision-making. Trust in the medical team was a huge part of patient choice; as decisions are based on past successes.

Within this theme of the shared decision making partnership comes the role of the ‘expert patient’. Well informed patients are considered to take on a more autonomous role in decision making.

**The Patient as an expert**

Health care professionals considered relapsed myeloma patients to be experts on their illness and its treatment. Patients themselves felt that they knew a lot about their illness. Health care professionals emphasised the importance of educating patients when first diagnosed. They all agreed that patients should know early about their disease and that their illness was incurable.

“...If you don't sit and meet with the person, educate them as well as you can and tell them what to expect. At the start it is an incurable thing so we need to be telling them that. Simply they accept it much better then.” (FG3, P1, Specialist Nurse).

Most relapsed myeloma patients were informed, knowledgeable and educated. However, this did cause discomfort for some nurses working on the day unit because they often felt they were not informed enough to provide adequate information to patients about their diagnosis and prognosis. As a result of this they often relied on the patients’ expertise and knowledge.

“I find it reassuring that they are experts because a lot of the time I am taking leave from them.” (FG2, P6 Nurse on Day unit).

This comes as a result of patients taking on a more active role in their condition. The majority of patients interviewed described seeking out further information about their disease and availing of other resources like the internet and books to gain further knowledge.

Some patients were happy with the information they received on their disease and treatment. They viewed themselves as experts and talked about living with their
myeloma and knowing what to look for. They described how keeping a close eye on the ‘proteins’ was a great way to monitor the disease as they knew that this indicated their response to the treatment.

“If you are taking the treatment it is going to cut down the proteins... you know and you are hoping it will.” (P4, Patient diagnosed for 8 years)

The expert patient was considered important to the majority of doctors as they ultimately revealed that it made their job easier as these patients tended to be more informed about treatments available.

**An unpredictable disease journey**

Myeloma remains an incurable disease. Questions remain around when to ‘draw the line’ especially in the case of a poor quality of life. Patients are on a chronic disease journey, often leading to a variety of symptoms and side effects. With more advancement in research, as our focus groups explained, more and more treatments are available often leading to patients dying in a harsh and unpredictable setting which is often distressing for both patients and health care professionals.

The unpredictable disease journey consisted of the many ways in which patients had to learn to live with an incurable disease. Patients with relapsed myeloma are on an individual journey and find many different ways of dealing with it psychologically; they are unwilling to give up too soon and often have an array of symptoms which are left unmanaged by palliative care. Sources of comfort were unique to each individual, yet were often inconsistent.

A great emphasis was placed on the chronic nature of myeloma, its unpredictable course and the challenges in planning care.

“There is an awful lot of uncertainty around their care... It’s very individualised as well.” (FG2, P5, Nurse on Day Unit).

There was strong agreement across all three focus groups on the importance of symptom management and the need for patient support in order to manage the features of myeloma as a chronic disease.

“If we are now starting to consider multiple myeloma as a chronic condition, we need to become better, I suppose at managing features of chronic conditions like fatigue and things like that which we would probably be not as good at asking about [symptoms]..” (FG1, P1, Haematologist).
The Incurable disease

Nurse specialists emphasised their role in stressing to patients from the outset that the disease was a lifelong incurable illness. They emphasised that patients are able to cope a lot better when informed about a relapse as a result of nearly expecting it.

“They [the patients] tend to accept it [relapse] more than patients that you would have seen with other conditions that relapse unexpectedly.” (FG3, P1, Specialist Nurse).

All doctors stressed the need for early introduction of palliative care in the patients’ illness journey but acknowledged the need for a greater understanding of what palliative care entailed.

“We should try to involve palliative care as early as possible to create an opportunity for palliative care to take over trust and understanding with the patient because... my understanding at the moment is that in Ireland many patients think of palliative care as end of life rather than management of complications, side effects or other confinements...” (FG1, P6, Haematologist).

Despite the progress made in recent years in the changing opinions of the role of palliative care, the nurses felt that patients still associated palliative care with dying.

“There is a perception that palliative care is the end.” (FG2, P4, Nurse on Day Unit).

The introduction of palliative care depended on each individual consultant and as a consequence the referrals to palliative care were inconsistent. Palliative care was acknowledged as being of sufficient benefit within this organisation, however health care professionals were quick to emphasise that they were rarely available as a result of an increasing burden from inpatient admissions.

“We have a number of myeloma patients here and I don’t ever think I have seen any of them being seen by palliative care, even just to link in with them.” (FG2, P1, Nurse on Day Unit).

This finding could suggest that palliative care services could be used more appropriately. Referrals are often not made until the end stage of life, which is an already frightening and distressing time for patients.

As well as this, myeloma patients were ‘fighters’ with a strong desire to live and accept all treatments offered, which may present challenges to discussions with patients on the need for palliative care intervention.

“They just want to keep living. You know they don’t want to give up. Their quality of life may be crap but they just want to keep going. There is one man in and out every single day and he is an hour’s drive up and down and it’s just there is no life to it like. But this is his life...” (FG2, P2, Nurse on Day Unit).
Many nurses in the day unit, who manage outpatient treatments for relapsed myeloma patients, questioned when the time was right to stop treatment. These nurses acknowledged relapsed myeloma patients’ fighting spirits but they also questioned when it was ethically appropriate to stop all treatment.

“You would wonder when the line would be drawn to say you need to spend time with your family and your friends…” (FG2, P1, Nurse on Day Unit).

There are often escalations of therapy at end of life in the relapsed myeloma setting and one nurse spoke about the distressing experience of looking after patients with end stage myeloma.

“I suppose looking back now the patients, like the deaths would be severe enough we would have to keep going in every so many hours with sub cuts and... it’s more so the multiple myeloma... those deaths I can just remember because they are on dialysis, they are just so ill…” (FG2, P2, Nurse on Day Unit).

While there was no consensus on when to introduce palliative care, it was agreed across all three focus groups that relapsed multiple myeloma patients needed this service. Both nurses and doctors agreed that a change in perception was needed in order for patients to view palliative care in a positive light and to facilitate a death with dignity and alleviate suffering.

“...we are trying to alleviate their suffering and that we are trying to tell them as it is that there is no more treatments and that you are facing death and maybe we need to looking at this with you now and see it as another thing to do…” (FG2, P6, Nurse on Day Unit).

Interestingly doctors had the general consensus that palliative care was primarily for symptom management.

**The individual Journey**

The incurable disease and unpredictable journey was individual for every patient. Patients with relapsed myeloma all dealt with their disease differently and it impacted on their life depending on their current disease status and how they dealt with the disease as an individual.

The chronic nature of the illness had an ongoing effect on the quality of life of patients with relapsed myeloma and permeated their daily lives.

“I don’t really go out much but even if you were out with company you wouldn’t be as lively. You would talk alright but you wouldn’t be as... it’s a setback. Any ailment is a setback; it’s a change in life. If you don’t have it you
have no worries... you are always on edge.” (P7, Patient diagnosed for 4 years).

Patients shifted from life orientated and disease orientated perspectives depending on other external factors such as disease progression.

“I don’t feel sick. If I did I would probably feel different about it. As far as I am concerned sometimes I wonder if I have cancer at all.” (P1, Patient diagnosed for 8 years).

“...when I get the right treatment or the proper treatment than I will have a better quality of life as opposed to the way it is...” (P7, Patient diagnosed for 8 years).

In an attempt to maintain a life oriented perspective, patients expressed the wish to live life as best they could. This included keeping busy and not thinking about their illness.

“It knocks you for a bit and then you just pick up and say right we attack it again and what you do, you can’t just sit in a corner and you can’t go crying and feeling sorry for yourself, you get up and go. I block it out and [myeloma] be gone. And I think if you are involved with something rather than hatching around the house or home... If you can be doing something and going that’s a help.” (P2, Patient diagnosed for 10 years).

Finding Comfort

Within the incurable and unpredictable disease journey, finding comfort was of major significance across all interviewee participants. Patients needed a source of comfort on their journey whether this was through finding their own methods of coping or adopting other comfort measures. However, health care professionals identified the obstacles to support provision.

Doctors and nurses considered emotional support for patients on their treatment journey as critical. However, interestingly the nurses commented that myeloma patient often do not avail of support services available to them, choosing to only avail of services if really necessary.

“I think when they are well they don’t want to have that intervention [support services] you know because they are well and you might encourage them to take up these services but they won’t because they are well.” (P1, FG2, Nurse on Day Unit).

Family and friends were also considered by the nurses to be crucial to the patients’ illness journey. However, some patients isolated themselves.
“It’s only myself that knows and they [family] don’t understand.” (P4, Patient diagnosed for 8 years).

“I am a bachelor. I live on my own. I don’t discuss my problems with others” (Laughs) (P5, Patient diagnosed for 5 years).

The majority of nurses working in the Day ward highlighted the informal support groups and companionship that developed among patients attending the day unit for treatment.

“I think they get great support from each other because they are all coming in so often here so often it’s like a support group for them and they talk...” (P6, FG2 Nurse on Day Unit).

The lack of a structured emotional support for patients attending the centre was a concern for both nurses and doctors. The centre only provides a limited psycho oncology service (sourced from a local charitable cancer support centre) and very ill patients often relied on the doctors and nurses for support. This often caused intense emotional effects for both doctors and nurses.

“...you come out of it [consult with terminally ill patient] literally feeling that you have lost 6 months in 1 hour of your life in there because you feel so awful about the consequences.” (FG1, P2, Haematologist).

For some patients, the hospital visits was their main source of support.

“I was just thinking of one lady in particular and her support was inside the hospital. She used to love coming to us to once a week or once a month or whatever. I forget how often she used to come to us but in the end she was very alone when it came to her mortality you know and that’s very difficult to manage... you try and encourage them to include somebody that is going to be supportive of them through that journey...” (FG3, P1, Specialist nurse).

Unsurprisingly, the long-term provision of support by specialist nurses over many years resulted in close nurse-patient relationships.

“I suppose the challenges really as specialists looking after patients with relapsed myeloma these patients are going on for a long time... you know everything about them you know when they got married, when they had kids, when they were transplanted for the first time...” (FG3, P1, Specialist nurse).

Finding comfort had differing perspectives for patient and health care professionals. It was considered part of the treatment process for these patients, however its service provision was severely lacking. Patients found comfort individually; that meant that some kept to themselves, while others found comfort from staff and others through informal support groups in the day services. However there was no consistent structure in place for emotional support established on site, which often resulted in distress for patients and health care professionals.
Discussion

Patients with relapsed myeloma live with the reality of their incurable disease. Although often described in the literature as “expert” patients (Maher and De Vries, 2011; Stephens et al., 2014), each new relapse brings with it new challenges and creates patient and caregiver vulnerability. The majority of care is undertaken as an outpatient resulting in an expectation that patients should take a primary role in the self-management of their disease (Kurtin et al., 2013). In the chronic illness trajectory, emphasis has remained around self management and patients being involved in decision making aspects regarding their care.

Myeloma patients often describe knowing that their disease had relapsed before even being told by a hospital staff (Maher and De Vries, 2011). Similarly, long term survivors of myeloma become accustomed to managing risk factors, managing the emotional toll of their diagnosis and mitigating the impact of their condition. As a result, becoming an ‘expert’ requires effort, planning and organization (Stephens et al., 2014).

The greatest impact that any chronic or incurable diagnosis has on an individual is the ability of the patient to live as ordinary a life as possible (Hale et al., 2007). Adapting to the role of an “expert” enables patients to reclaim their self and their full identity while receiving recognition and support for self-monitoring practices (Koch et al., 2004). There were some patients in this study who did not want to know about their illness and the main focus for them was to keep busy and ignore their illness until such time as they felt unwell. Paterson (2001) describes this as ‘the shifting perspectives’, where patients with a chronic illness shift between life and disease orientated perspectives depending on different aspects such as progression of disease, feeling well and personal consequences.

Resources such as the internet enables patients to access a range of information regarding further treatments and recommendations. However, despite myeloma patients having a vast volume of information available to them, they still place significant trust in their doctors to guide them for future treatment. A similar finding is reported by Bulsara et al., (2004), where patients with haematological cancers (n=2 with myeloma) and their spouses were interviewed. Many said that even though they were given treatment options, they would nevertheless rely totally on the decision of their specialist doctor. This can be difficult for doctors who often prefer patients to take ownership because it lessens the sense of guilt when treatment outcomes are disappointing. However, patients are considered more likely to try a new treatment or medication if there is a high level of trust in the doctor’s expertise (Thom et al., 2004). This trust in their doctors may explain why patients with relapsed myeloma are willing to partake in clinical trials and opt for further treatment options. Despite this, haematology patients report that this trust is ‘earned’ over time (Bulsara et al.,
The availability of further treatments to patients has resulted in a longer life expectancy for many patients and myeloma is considered a chronic incurable condition rather than a terminal illness. The advancements in treatments has led to the majority of patients interviewed having had multiple lines of treatments. As a result, patients with relapsed myeloma are living with long term symptoms such as back pain, neuropathy and often steroid induced side effects such as oedema (Molassiotis et al., 2011a) and each new relapse brings with it a certain amount of vulnerability and reduced self esteem (Stephens et al. 2014). In this study, nurses and doctors emphasised the need for support for patients going through the myeloma journey. Referrals to psycho oncology services should be central in patients’ management (Molassiotis et al., 2011a; Molassiotis et al., 2011b; Lobban and Perkins, 2013).

Myeloma patients are described as “fighters” in their battle against the disease and are willing to take chances on new treatments (Maher and De Vries, 2011). However, relapsed myeloma patients’ periods of remission become shorter as they succumb to progressive disease (Stephens et al., 2014). As a result, palliative care may need to be considered for symptom management and support. It is important for clinicians to introduce palliative care at an appropriate time in the disease journey. Most patients with hematological malignancies do want information on palliative care before it is needed to allow them think about the issues ahead and plan for their family (McGrath, 2013). These patients are often aware that they will need palliative care at some stage and for those who know about the service, it gives them confidence that even if their referral was delayed until the final stage they would have enough information to know what to do (McGrath 2013). However, salvage therapies see many patients continuing to have treatments in the later stages of the disease which often gives rise to false hope and denial from both patients and health care professionals (Howell et al., 2010). Most haematology patients face ending life amid escalating technology in the curative system without access to palliative care (McGrath 2014). For some haematology patients, quantity of life is placed ahead of quality of life (McGrath 2002). This places significant emphasis on doctors’ and nurses’ knowledge of each patient to know their individual preferences.

Patients with haematological malignancies are not receiving appropriate or timely referrals to palliative care (Joske and McGrath, 2007, McGrath 2014). The major obstacle to the integration of palliative care and haematology is believed not to be clinical characteristics of the patient population but rather attitudes of the health professionals providing the care (McGrath, 2002; McGrath and Howlea, 2006). However, encouragingly, these findings reported here suggest a shift in the attitudes of doctors and nurses towards early introduction of palliative care for relapsed myeloma patients.
Conclusion

This study has explored relapsed myeloma patients' views on their illness, and nurses' and doctors' views of the issues arising for these patients. Patients with myeloma face an uncertain future and often live with a sense of fear at not knowing when they will become ill again. Myeloma patients are now living longer therefore it is essential that long term supportive care needs and quality of life issues are addressed proactively (Molassiotis et al., 2011a). Myeloma patients have higher levels of symptoms and problems compared to any other haematological cancers (Johnsen et al., 2009; Molassiotis et al., 2011a). However, this group of patients are not referred to palliative care in the same way as patients with non-haematological cancers and there is often an escalation of therapy at end of life (McGrath and Howela, 2006; Howell et al., 2010; McGrath, 2014). Palliative care's function was primarily associated with symptom management by health care professionals yet they believed that patients perceived it to be care received at end of life. Patients’ perceptions of palliative care as end of life treatment may represent the “fighters” role they take on, unwilling to give up on life too soon and resulting in escalations of therapy in the final stages of life.

Patients with relapsed myeloma experience a very individual journey. Both health care professionals and patients acknowledged this and often it was perceived as a direct barrier to implementing the ideal holistic plan of care which encourages patients to self manage. Patients were seen to become more autonomous in their care, with health care professionals welcoming this; however patients felt they had to seek information elsewhere despite this. There were similar feelings across both health care professional and patient interviews regarding the complexity of the illness and the emotional journey that patients experience, the sense of unwillingness to give up on life and the unpredictability of what faces these patients.

This study is important as it further adds to what known already about the issues facing patients with this incurable disease and identifies areas where improvements need to take place in order to provide holistic care of patients with relapsed myeloma.

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References


McGrath, P., Patton, A. M. 2010. But you didn’t tell me this: Australian patients’ experiences with obtaining information on the impact of steroid use in Haematology. The Hong Kong Nursing Journal 44 (2), 18-27.


Appendix 1: Interview Guide

Patients

1. Tell me about your experience of the Care you are currently receiving.
   
   Probe: Ask them about their experience of the care they receive. Does it affect you, your family members or friends?
   
   Prompt: How do they feel about the care they are receiving?

2. Is there anything that you feel needs improvement in your care?
   
   Probe: More Referrals to other specialities, quicker access to A&E.
   
   Prompt: If you were looking for more support or better care what do you think would help?

3. Do you feel that your Doctor involves you in decisions regarding your care?
   
   Probe: What are your thoughts about being involved in decisions regarding your care?
   
   Prompt: Can you tell me about how you make decisions regarding your care?

4. What has been most difficult for you since you began your 2nd treatment?
   
   Probe: Tell me how it has been for you since you started your second line of treatment.
   
   Prompt: How did it make you feel?

5. Have you been offered any other forms of Support/Care/Referrals to help you during your illness?
   
   Probe: Psychosocial Care, Emotional, Financial, Palliative Care etc.
   
   Prompt: What other support has been offered to you?

Other Prompts:

1. How did that make you feel....
2. Can you tell me a bit more about this....
3. Is there anything else you would like to add....
Appendix 1: Interview Guide

Doctors

Questions

1. What has been your experience of working with relapsed multiple myeloma patients been?
2. Can you tell me what you believe is most important in their care?
3. Do you believe there is room for improvement in their care?
4. Multiple Myeloma is a life limiting condition, what are your views on involving other specialities such as Palliative Care in the Care of these patients?
5. Do you involve patients in decisions regarding their care?

Probes

"Can you talk about that more?"

"Help me understand what you mean"

"Can you give an example?"

"Would you explain further?"

"Would you give an example?"

"I don't understand."
Appendix 1: Interview Guide

NURSES

QUESTIONS

1. What has been your experience of working with patients with relapsed multiple myeloma?
2. Can you tell me what you believe is most important in their care?
3. Do you believe there is room for improvement in their care?
4. Multiple Myeloma is a life limiting condition, what are your views on involving other specialties such as Palliative Care in the Care of these patients?
5. Would you consider patients to be well informed regarding their treatments and current care plan?