



# An exploratory study of the care experience of patients diagnosed with multiple myeloma



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- Multiple Myeloma accounts for 15% of all haematological malignancies in Australia
- In 2016, an estimated 1,050 Australian men and 735 women will be diagnosed with multiple myeloma
- 995 deaths (570 men, 425 women)
- Median age at diagnosis is 65-70 years
- By 2025 the rate of diagnosis is expected to rise by 50%

- Multiple Myeloma is universally incurable
- Significant increase (17%) in relative survival over past 20 years for those aged <65 years
- Improvement in outcomes for older patients ineligible for autologous stem cell transplantation(ASCT) has been much less (3.3%)

(Wildes et al, 2014: JCO)



- Myeloma patients experience pain, bone pain, fractures, fatigue, neuropathy; anaemia, cachexia, bone marrow failure, renal failure, anxiety, depression, insomnia, aches, infection, distress (Cachia, et al, 2012: BMJ Support Palliat Care: Rosen et al, 2013: Cancer)
- Compared to younger patients with myeloma, patients aged over 65 years score worse on social, physical and role functioning, and global health/QoL, fatigue, pain and dyspnoea (EORTC QLQ-C30)( $p < 0.01$ ) (Van der Poel et al, 2015: Ann Hematol)
- In an analysis of HRQoL data from 16,095 cancer survivors and 1, 224, 529 individuals without cancer (SEER/MHOS), survivors of myeloma and pancreatic cancer scored lowest – 1 standard deviation or more below that of others without cancer (Kent et al, 2015: Cancer)



Financial impact: High use of novel agents and extended treatment duration

In a study of 100 US patients, almost a quarter of patients (21/21%) had borrowed money to pay for medications

(Huntington et al, 2015: Lancet/haematology)

Links between financial hardship and quality of life (Zafar et al, 2014: J Onc Practice) and if impact is severe, between hardship and mortality rate (Bansal et al, 2015: Proc Am Soc Clin Oncol)

Little research into the patient and carer experience of living with a diagnosis of multiple myeloma.

- Molassiotis et al, 2011: Supp Care Cancer

20 patients; 16 carers; 5 year survivors

- Maher et al, 2011: EJCC

8 patients with relapsed myeloma

- Potrata et al, 2011; Psychooncology

15 patients at differing stages

- Baz et al, 2015: Supp Care Cancer

20 patients at differing stages



# Key themes

Current and future concerns; effects of myeloma in daily life; practical, functional and emotional coping; unmet needs

Overarching theme: coping and managing with myeloma and its consequences

Uncertainty; Importance of social support  
Distress linked to threat; cognitive impairment

HRQL: impact of pain and fatigue on ADLs; on family and everyday activities; impact of fear on leisure activities; on independence: Impact of clinic visits; mode of treatment administration



- **Aim:** *To explore the unmet physical and supportive care needs of people, aged over 65 years ineligible for ASCT, diagnosed with myeloma over a 6-month period*
- **Objective:** *To use data gathered to inform a model of patient-centred case management to be tested in a future study*



## A prospective, exploratory, mixed-methods study

- Patients completed a series of validated measures at baseline (T1); at 8-12 weeks post baseline (T2), and at 6 months post baseline (T3).
- Measures included:
  - Hospital Anxiety and Depression Scale
  - Morisky Medication Adherence Scale – 8 item
  - Distress Thermometer & Problem Checklist
  - EORTC QLQ-C30 & MY-20



- *Patients and a carer/partner were invited to take part in a semi-structured interview after completion of T3 measures*
- Consultants referring patients and patients GPs were also invited to participate



- Principles of grounded theory were maintained
  - Participants interviewed in naturally occurring setting – their home
  - Using open-ended and flexible questions that could be modified as research progressed
  - Identification of themes and codes without predefined coding categories
  - Interviews were audio-recorded; transcribed verbatim, and analysed by MK

- Following ethics approval, patients were recruited from 4 settings – 2 metro and 2 regional
- Eligibility criteria: definitive diagnosis of Multiple Myeloma; be over 65 years; ineligible for autologous stem cell transplant
- Patients were referred to the study RA via their consultant
- The study RA contacted patients, explained the study and sent out PICF. If appropriate, a carer/partner was also invited to take part



Number of patients referred n=20 (100%) ?	Not eligible n=1? Declined n=2? Deceased n=2?
Number of patients recruited n=15? ?	1 patient deceased prior to T1?
T1 (3-6 weeks) n=14? ?	1 deceased, 1 progressed/unwell, 1 declined further participation?
T2 (8-12 weeks post T1) n=11? ?	1 deceased?
T3 (6 months post recruitment) n=10? ?	?
Interviews?	10 patients? 4 family members?

?



# Characteristics of our sample

	T1 (n=14)	T2 (n=11)	T3 (n=10)
Newly diagnosed	8	7	6
Relapsed disease	6	4	4
Age (median and range)	Median: 71 (66-90)		
Male	10	8	7
Female	4	3	3
Metropolitan treated	11	8	7
Metropolitan residence	11	8	7
Lived by themselves	2	2	2
English first language	14	11	10



- Cancer and self identity
- Coping with cancer and treatment-related problems
- Social support
- Living with uncertainty

- “I’m gonna have it the rest of ...as long as I live”(006)
- “Once all the treatment started it was quite good for me ..and I really felt like I made a difference...since the relapse it’s hit me much harder because I’ve got nothing to do now..”(008/wife)
- “As for us, we’re just going along with seeing the haematologist, trusting him and life’s in his hands actually... what else can you do?” (016)



- “I’ve been a football umpire all my life, fifty odd years with VFL and I retired from work and then I find out, you know, two years down the track that I’ve got myeloma. And yeah so I went from being a very healthy fellow I thought, to having to go to hospital all the time to have treatment” (017)
- “There are implications from her fragility that I now understand completely but other people don’t and they turn that into aggression towards you.. This is probably quite common but this is a new learning experience for us....[I’m] respecting her wishes (002/son)



- “Pain, it’s tiredness. I’m really careful with the pain because as soon as I feel a twinge I’ll come and lie down....I’m not prepared to push myself and get into really bad pain and have to take an Endone because ...that’s goodbye for the rest of the day” (001)
- “There hadn’t been much of a change and then the Thalidomide treatment disabled her...It’s time consuming in that she cannot be left alone now ever ...there’s one problem ..you don’t get very much sleep” (002/son)
- “ it’s got worse and worse quick smart, my legs wouldn’t carry me around like my knees would go under me and they were shaking”(006)



- “This neuropathy thing ... has come on really badly today, it’s been a little bit in this hand but now it’s in both... that’s not the sort of thing to put you in hospital is it? ... but that’s the thing of being on your own... what happens if something’s not quite right” (001)
- “It’s a very expensive thing being sick, very expensive” (001)
- “For start off I had some tablets, like there was 19 tablets and it really knocked me around”(006)
- “It annoys me that I’ve lost a certain amount of strength and ability to work manually for eight or nine hours a day”(008)
- “ I’d just like to see him get a lot better .. Have more energy. I am so worried about him sleeping all the time, maybe the sleep is helping him, I don’t know, I really don’t know “(006/wife)



- “Two of them at the moment are overseas ... my two stalwarts, so that makes it a bit difficult , but I don’t have any other family...I’ve got a neighbour whose been an absolute saint, she drives me to the hospital.. And I’ve insisted I pay her” (001)
- “I had the benefit ... great support from family and wonderful, wonderful doctors...I was told what I was going to have to go through...” (010)
- “She takes me everywhere, to the hospital.. She’s involved all the time. All the treatments I go she drives me, drives me home” (017)



- “I went on a disability pension, quit my job, which was a blessing: (010)
- “For me it’s been really helped by ... having my son is a doctor ...that provides additional reassurance and explanation and him coming along to meet the haematologist”(009)

- “Nobody can say, you know, the question that probably everyone wants to know is how long have I got, you don’t know and that’s a question that no one can answer” (001)
- “It’s different, it’s not the same all the time”(006)
- “The other impact, one of uncertainty from the point of view of not being able to make plans, to plan for an overseas holiday in nine months” (008)
- “There’s the initial worry you know, am I going to survive and for how long...but you can’t be necessarily definite as to how things will transpire in the end, so you have this sort of uncertainty”(009)



- “ We don’t bother, can’t go or don’t go anywhere much whereas we used to travel quite a bit” (016/wife)
- “I was seeing him [haematologist] weekly and then when he took me off the chemotherapy I’ve seen him monthly...that has been one thing, there’s a lot of managing your own health involved with this condition” (001)
- “ I’m wondering how long it’s gonna last...but it’s not worrying me. I’m old and I’ve got to die some day and I’m preparing for that...you never eradicate it ... but you can control it to a point” (016)



What does this tell us about the essential components of a model of care designed around the needs of patients and their support networks?



- Prospective, longitudinal supportive care needs assessment
- Prompt referral and coordination within and across sectors
- Patient-initiated and nurse-led
- Patient and family/carer focused
- Remote monitoring and intervention
- Health literacy and self management
- State or territory based roles – hub and spoke model
- Experience focused and outcomes driven



# What's next?

- Competitive research funds to develop and pilot test a centralised model of case management for older people living with multiple myeloma



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