

# Patients' Experiences With Multiple Myeloma: A Meta-Aggregation of Qualitative Studies

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**Problem Identification:** To systematically review qualitative evidence regarding patients' experiences of living with multiple myeloma. The main objective was to gain structured understanding of this experience, which is a prerequisite for advancing nursing care and ensuring it is effective.

**Literature Search:** Qualitative research articles from January 2005 to March 2016 were located in CINAHL®, PubMed, and Scopus. Supplementary resources were found by scrutinizing reference lists and performing citation tracking. All included articles fulfilled predetermined criteria.

**Data Evaluation:** Three reviewers independently assessed the risk of methodologic bias by using the Joanna Briggs Institute (JBI) Qualitative Assessment and Review Instrument. The JBI methodology of meta-aggregation was used to synthesize findings.

**Synthesis:** Eleven studies fulfilled the eligibility criteria. From these, 84 findings were extracted. Each finding was assigned a level of credibility: unequivocal, credible, or unsupported. Findings were grouped into 11 subcategories and synthesized further into four main categories: (a) distress, (b) a different body, (c) coping, and (d) contributions of other people.

**Conclusions:** Patients with myeloma require a different form of follow-up compared to patients with many other cancers because of its chronic nature. Results demonstrate that widespread physical, emotional, and social challenges were experienced by patients throughout their illness trajectories, even in periods of remission. Nursing care should incorporate knowledge of patients' experiences.

**Implications for Practice:** The results provide directions for nurses to improve supportive strategies in the care of patients with multiple myeloma. The categories provide a useful framework for developing clinical assessment tools.

Patients diagnosed with multiple myeloma need to adjust to many changes throughout their illness trajectories. Although several qualitative studies have shown that the disease has a substantial impact on patients' life situations and possibilities (Dahan & Auerbach, 2006; Kelly & Dowling, 2011; Maher & de Vries, 2011), no study has synthesized these research findings.

Multiple myeloma is a rare cancer in which plasma cells accumulate in the bone marrow and secrete an abnormal immunoglobulin (paraprotein). Although only accounting for 1% of all cancer types, multiple myeloma is the second most common hematologic malignancy (Lobban & Perkins, 2013; National Comprehensive Cancer Network [NCCN], 2016; Stephens, 2009). Myeloma usually affects patients in late adulthood, which is reflected in the average age of 70 years at diagnosis (Genadieva-Stavric, Cavallo, & Palumbo, 2014). Advancements in treatment, with development of novel drugs used in combination with cytostatic therapy, autologous stem cell transplantation, and improved supportive care, has

led to increased survival of patients with myeloma (Genadieva-Stavric et al., 2014; Röllig, Knop, & Bornhäuser, 2015). Despite these improvements, patients are still challenged with burdensome symptoms, both related to the disease itself and side effects of treatment, and, therefore, need to modify their daily life activities substantially (Jordan et al., 2014).

The clinical course of myeloma is characterized by fluctuations and unpredictability. After treatment, patients may experience periods of clinical remission, but they never know when the next exacerbation will occur. With time, patients may become entirely unresponsive to treatment (Lobban & Perkins, 2013). Typical symptoms that patients with multiple myeloma experience are fatigue, pain, neuropathy, and insomnia (Boland et al., 2013), along with complications such as bone lesions, hypercalcemia, anemia, kidney damage, and immunosuppression (Stephens, 2009).

Researchers have studied the health-related quality of life (HRQOL) of patients with myeloma at different time points. Even early in treatment, patients experience a considerable need for professional support—support that is not directed toward only treatment-related concerns. To illustrate, newly diagnosed patients who were eligible for intensive treatment, such as stem cell transplantation, described an array of concomitant physical and psychosocial symptoms such as emotional distress (e.g., anxiety, depression) and decreased functional performance (Coleman et al., 2011; Sherman, Simonton, Latif, Spohn, & Tricot, 2004). Similar results have also been found in those with longer disease duration (Jordan et al., 2014; Molassiotis, Wilson, Blair, Howe, & Cavat, 2011b). Current evidence shows that, at all phases of the disease, patients may experience a considerable symptom burden that negatively influences their HRQOL (Osborne et al., 2012). Other studies have shown that being in the first treatment-free interval (rather than other treatment phases) and longer periods of remission were associated with improvement in HRQOL (Acaster, Gaugris, Velikova, Yong, & Lloyd, 2013). In spite of a generally better situation during remission, patients are still required to deal with enduring problems (Boland et al., 2014).

Nurses have an important role in providing patients and their families with information and support, as well as in making holistic assessments of physical, practical, and emotional needs (Faiman, 2007). They play an important role in managing side effects and complications and helping patients and their loved ones with supportive care (Lobban & Perkins, 2013). This care aims to enhance HRQOL (Faiman, 2007; Lobban & Perkins, 2013; Stephens, 2009). To ensure that the care corresponds to patients' expectations, nurses must gain insight into the multiple challenges

that patients are confronted with. Therefore, research results should be structured in a pragmatic way that makes it possible to use them in clinical care.

The aim of this review was to synthesize results of existing qualitative studies on patients' experience of living with multiple myeloma. The objective was to gain a comprehensive understanding of this experience so that nursing care can more accurately target patients' needs. The research question was formulated according to the Sample, Phenomenon of Interest, Design, Evaluation, and Research type (SPIDER) tool (Cooke, Smith, & Booth, 2012): How do patients with multiple myeloma describe their experience of living with the disease, their daily challenges and helpful strategies, from diagnosis onwards, in existing qualitative studies?

## Methods

The design of this review adhered to the Joanna Briggs Institute (JBI) methodology of meta-aggregation to allow a systematic synthesis of qualitative evidence of patients' experiences with multiple myeloma. Although the method of meta-aggregation mirrors the processes of a quantitative review, it retains the characteristics of qualitative research traditions (Hannes & Lockwood, 2011; JBI, 2014). Also, rather than reinterpreting findings of primary qualitative studies, this methodology discovers the practicality and usability of research findings across studies (JBI, 2014; Korhonen, Hakulinen-Viitanen, Jylhä, & Holopainen, 2013). To ensure clear reporting of the method, review findings, and implications, the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) protocol was followed (Liberati et al., 2009).

## Search Strategy

The search strategy was structured according to SPIDER to enable more precision in the search strategy and location of relevant studies to answer the research question (Cooke et al., 2012).

A preliminary search was conducted using the Cochrane, JBI, PubMed, and Google Scholar® databases to identify the presence of existing systematic reviews. No existing syntheses of qualitative studies were found. Therefore, a systematic search was conducted in PubMed, CINAHL®, and Scopus. Additional studies were located by scrutinizing the reference lists of included studies and performing citation tracking in Google Scholar. A representation of the search process can be found in Figure 1.

## Eligibility Criteria

Studies were deemed eligible if they were published peer-reviewed qualitative studies on patients' experiences

of living with multiple myeloma. Study populations had to be adult (aged 18 years or older) and diagnosed with multiple myeloma at any stage of the disease. Only English-language studies were considered, with a publication date from January 2005 to March 2016. Older studies were excluded because of advancements in treatments, which have led to increased survival (Genadieva-Stavric et al., 2014). Studies with unsupported results, such as unclear themes and/or lack of participants' quotations, were excluded.

Study Selection

All abstracts were screened for suitability by the first author (BH). Full-text articles were retrieved for the chosen abstracts. Two authors (BH/KB) independently assessed the articles in their entirety, matching them against the inclusion criteria and evaluating the risk of methodologic bias. A third reviewer (MK) validated their findings. Any disagreement was resolved by consensus. Additional resources were found by scrutinizing the reference lists of included studies and conducting citation tracking. Potential new studies identified through this process were subjected to all of the previously mentioned steps. All full-text articles that initially were rejected went through a second evaluation by all authors to ascertain whether that rejection was justified.

Quality Appraisal

Methodologic quality was assessed using the 10-item standardized critical appraisal instruments from the JBI Qualitative Assessment and Review Instrument (JBI-QARI) (JBI, 2014). This appraisal was used by the researchers to guide the interpretation and presentation of the results.

Data Extraction and Synthesis

Data extraction and synthesis were accomplished in agreement with the four phases of meta-aggregation: (a) gathering findings, themes, metaphors, and categories from all studies; (b) aggregating findings based on similarity in meaning and by placing them into relevant subcategories; (c) merging subcategories into main categories; and (d) presenting results in a way that provides pragmatic lines of action (Hannes & Lockwood, 2011; JBI, 2014).

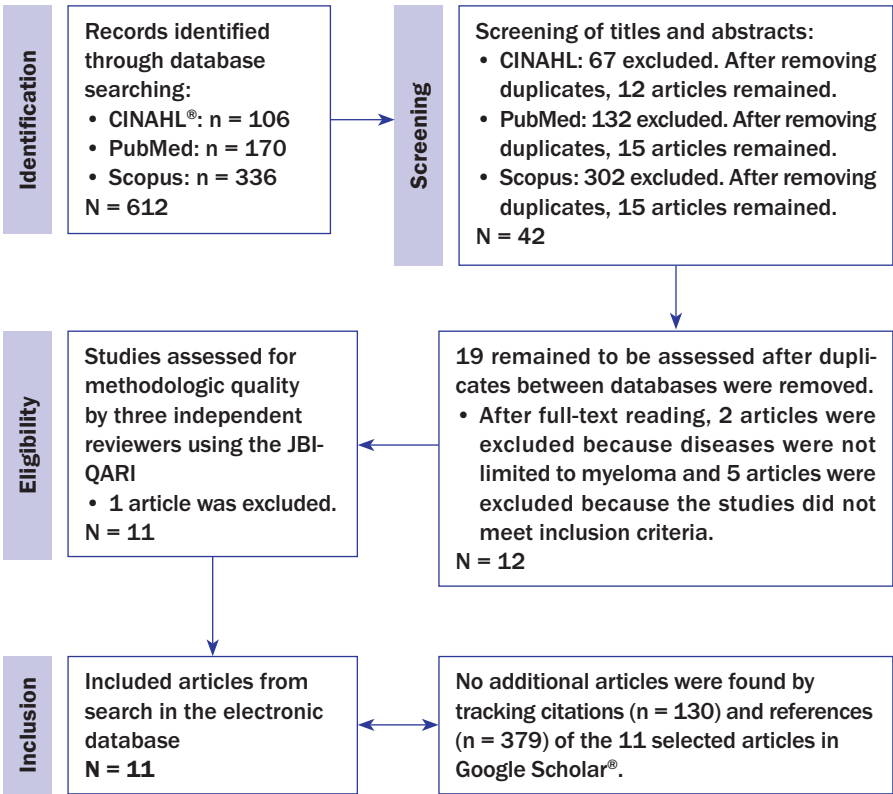
Results

Selected Studies

The electronic database search found 612 potential articles. A total of 19 articles remained after screening the titles and abstracts and adjusting for duplicates within and between databases. Ultimately, 11 studies were included (see Table 1).

FIGURE 1. Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) Flow Diagram of Review Study Selection

JBI-QARI—Joanna Briggs Institute Qualitative Assessment and Review Instrument



The studies included a total of 140 patients. The most common qualitative methodology of the reviewed studies was grounded theory. Two studies used the same participants. However, their results revealed different facets of the myeloma experience. The study by Potrata, Cavet, Blair, Howe, and Molassiotis (2010) focused primarily on cognitive impairments, whereas Potrata, Cavet, Blair, Howe, and Molassiotis (2011) concentrated on other distressing experiences.

Assessment of Methodologic Quality

From the 11 included studies, 84 findings were extracted. All of these findings were appraised as being unequivocal, apart from one that was found to be credible (see Table 2).

The 84 findings were grouped into 11 subcategories from which four main categories emerged, reflecting the experience of living

with myeloma. The presentation of results is similar to a previous review using similar methodology (Burckhardt, Belzner, Berg, & Fleischer, 2014). In the following sections, major results within each of the four synthesized categories are described. Illustrative quotations are presented from the original studies within the four main categories respectively, along with their relevant references (see Appendices A–D).

## Synthesis 1: Distress

This synthesis is based on 28 findings grouped into four subcategories (see Figure 2).

**Diagnosis of an unknown disease:** Receiving the diagnosis of myeloma was a huge blow, where patients experienced a sudden confrontation with their

own mortality. Life had changed forever. Most had never heard of the disease prior to diagnosis and were uncertain of what challenges they would be confronted with. The fact that other people also lacked knowledge of the disease prevented the patients from receiving questions and feedback from their friends and family. This accentuated the strangeness and feeling of isolation in initiating a changed life with myeloma. One of the first actions that patients carried out after receiving their diagnosis was to gather useful information about the disease and its possibilities for treatment. It was important for them to become well acquainted with the disease.

**Living with uncertainty:** Living with an incurable cancer and a relentless threat of relapse was a

**TABLE 1. Characteristics of Included Studies**

Study	Country	Purpose	Methodology	N	Methods
Baz et al., 2015	United States	Explore the experience of myeloma, treatment, and the impact of these on health-related quality of life.	Thematic analysis	20	Semistructured telephone interviews
Craike et al., 2013	Australia	In-depth understanding of the physical activity experiences and perceived benefits and barriers to physical activity for patients with myeloma	Grounded theory	24	Semistructured interviews
Dahan & Auerbach, 2006	United States	Understand the emotional impact of multiple myeloma, as well as the impact of peripheral blood stem cell transplantation.	Grounded theory	6	Interviews
Kelly & Dowling, 2011	Ireland	Explore patients' lived experience of being diagnosed with myeloma.	Hermeneutic phenomenology	11	Interviews
Maher & de Vries, 2011	United Kingdom	Explore the experience of people with relapse myeloma specifically to determine how the experience of living with relapsed myeloma affected quality of life.	Hermeneutic phenomenology	8	Open-ended unstructured interview
Molassiotis et al., 2011a	United Kingdom	Explore the experience of living with myeloma after completion of treatments.	Grounded theory	20	Semistructured interviews
Potrata et al., 2010	United Kingdom	Obtain a more in-depth understanding of cognitive impairments and concerns as described by patients with myeloma and strategies used to cope with them.	Grounded theory	15	Semistructured interviews
Potrata et al., 2011	United Kingdom	Gain greater insight into the symptoms and distressing experiences of patients living with myeloma.	Grounded theory	15	Semistructured interviews
Stephens et al., 2014 <sup>a</sup>	Australia	Experiences of long-term survivors of multiple myeloma	Grounded theory	11	In-depth interviews
Vlossak & Fitch, 2008	Canada	Gain an understanding of the impact of multiple myeloma on the patient and family.	Qualitative study	20	In-depth telephone interviews
Wagland et al., 2015	Australia	Explore the diagnosis and experience of younger women living with multiple myeloma and their geographic disadvantage.	Interpretative phenomenology	5	Semistructured interviews

<sup>a</sup> Only the qualitative section concerning patients with myeloma was used from the study.



**TABLE 2. Summary of Review Findings**

Study	Findings	Numbered Findings
Baz et al., 2015	4 (1–4)	<ol style="list-style-type: none"> <li>1. Impact on HRQOL: Impact of pain</li> <li>2. Impact on HRQOL: Impact of fatigue</li> <li>3. Impact on HRQOL: Impact of other symptoms</li> <li>4. Impact on HRQOL: Impact of multiple myeloma treatment</li> </ol>
Craike et al., 2013	8 (5–12)	<ol style="list-style-type: none"> <li>5. Current participation in physical activity and change from prediagnosis: Current type and intensity of physical activity</li> <li>6. Current participation in physical activity and change from prediagnosis: Change from physical activity prior to diagnosis</li> <li>7. Perceived benefits of physical activity: Recovery from treatment/disease</li> <li>8. Perceived benefits of physical activity: Psychological health               <ol style="list-style-type: none"> <li>a. Cognitive improvement</li> <li>b. Affective changes</li> </ol> </li> <li>9. Perceived benefits of physical activity: Enjoyment</li> <li>10. Perceived benefits of physical activity: Social factors</li> <li>11. Perceived barriers to physical activity: Multiple myeloma symptoms and side effects of treatment</li> <li>12. Perceived barriers to physical activity: Low self-motivation and lack of interest in physical activity</li> </ol>
Dahan & Auerbach, 2006	25 (13–37)	<ol style="list-style-type: none"> <li>13. Diagnosis: Two catalysts to diagnosis</li> <li>14. Diagnosis: Shock</li> <li>15. Diagnosis: Looking death in the face</li> <li>16. Diagnosis: Deciding on a plan of action</li> <li>17. Treatment: Reaction to transplant</li> <li>18. Treatment: Physical immobilization</li> <li>19. Treatment: Violation and dehumanization</li> <li>20. Treatment: Isolation</li> <li>21. Treatment: Sense of vulnerability</li> <li>22. Treatment: Burden on family</li> <li>23. Network of safety: Confidence in doctor</li> <li>24. Network of safety: Appreciation for the cancer center</li> <li>25. Network of safety: Overwhelming social support</li> <li>26. Network of safety: Strong family presence</li> <li>27. Network of safety: Relating to other patients with cancer</li> <li>28. Network of safety: Personal coping</li> <li>29. Recuperation: Strengthened body and spirit</li> <li>30. Reflection/new existence: Changed body</li> <li>31. Reflection/new existence: Less hope for future treatments</li> <li>32. Reflection/new existence: Enduring threat of relapse</li> <li>33. Reflection/new existence: Anticipating loss</li> <li>34. Reflection/new existence: Acceptance</li> <li>35. Reflection/new existence: Identifying resilience in oneself</li> <li>36. Reflection/new existence: Strengthened connection to others</li> <li>37. Reflection/new existence: Living while dying</li> </ol>
Kelly & Dowling, 2011	10 (38–47)	<ol style="list-style-type: none"> <li>38. Lived body, a changed body: Alopecia</li> <li>39. Lived body, a changed body: Fatigue</li> <li>40. Lived space, living in limbo: Living with an unknown cancer</li> <li>41. Lived space, living in limbo: Stigma of cancer</li> <li>42. Lived space, living in limbo: Loss</li> <li>43. Lived space, living in limbo: Feeling lucky</li> <li>44. Lived time, time is precious: Fear of recurrence</li> <li>45. Lived time, time is precious: Limited time with healthcare professionals</li> <li>46. Lived relations, significance of support: Family support</li> <li>47. Lived relations, significance of support: Protecting others</li> </ol>

*Continued on the next page*

**TABLE 2. Summary of Review Findings (Continued)**

Study	Findings	Numbered Findings
Maher & de Vries, 2011	9 (48–56)	48. Living with uncertainty 49. Intuitive knowing 50. Maintenance of normalcy 51. Adjustment to illness 52. Hope 53. Effects of treatment 54. Trusting healthcare professionals 55. Fighting spirit 56. Receiving the bad news
Molassiotis et al., 2011a	4 (57–60)	57. Coping with and managing myeloma and its consequences: Current and future concerns 58. Coping with and managing myeloma and its consequences: Effects of myeloma in daily life 59. Coping with and managing myeloma and its consequences: Practical, functional, and emotional coping 60. Coping with and managing myeloma and its consequences: Unmet needs
Potrata et al., 2010	2 (61–62)	61. Cognitive impairments as permanent interference 62. Coping strategies
Potrata et al., 2011	5 (63–67)	63. Distress from experienced symptoms 64. Distress from body image changes 65. Distress caused by family and friends 66. Distress from myeloma-related information 67. Distress from stem cell transplantation
Stephens et al., 2014	4 (68–71)	68. Risk work: Risk to well-being 69. Risk work: Risk of injury 70. Risk work: Risk of infection 71. Emotional work
Vlossak & Fitch, 2008	10 (72–81)	72. The diagnosis was shocking and unexpected. 73. There are few options for treatment. 74. Worry about the family and how they will handle the diagnosis 75. Treatment is difficult, long, and very complex. 76. Fatigue can be overwhelming. 77. Loss of independence 78. Change in self-concept/self-image 79. Obsession on how and when the end will come 80. Fear of recurrence 81. Rationalization of changes in their hopes for the future
Wagland et al., 2015	3 (82–84)	82. Isolation due to living with a rare cancer 83. Isolation within the myeloma population 84. Isolation due to disease effects and treatment

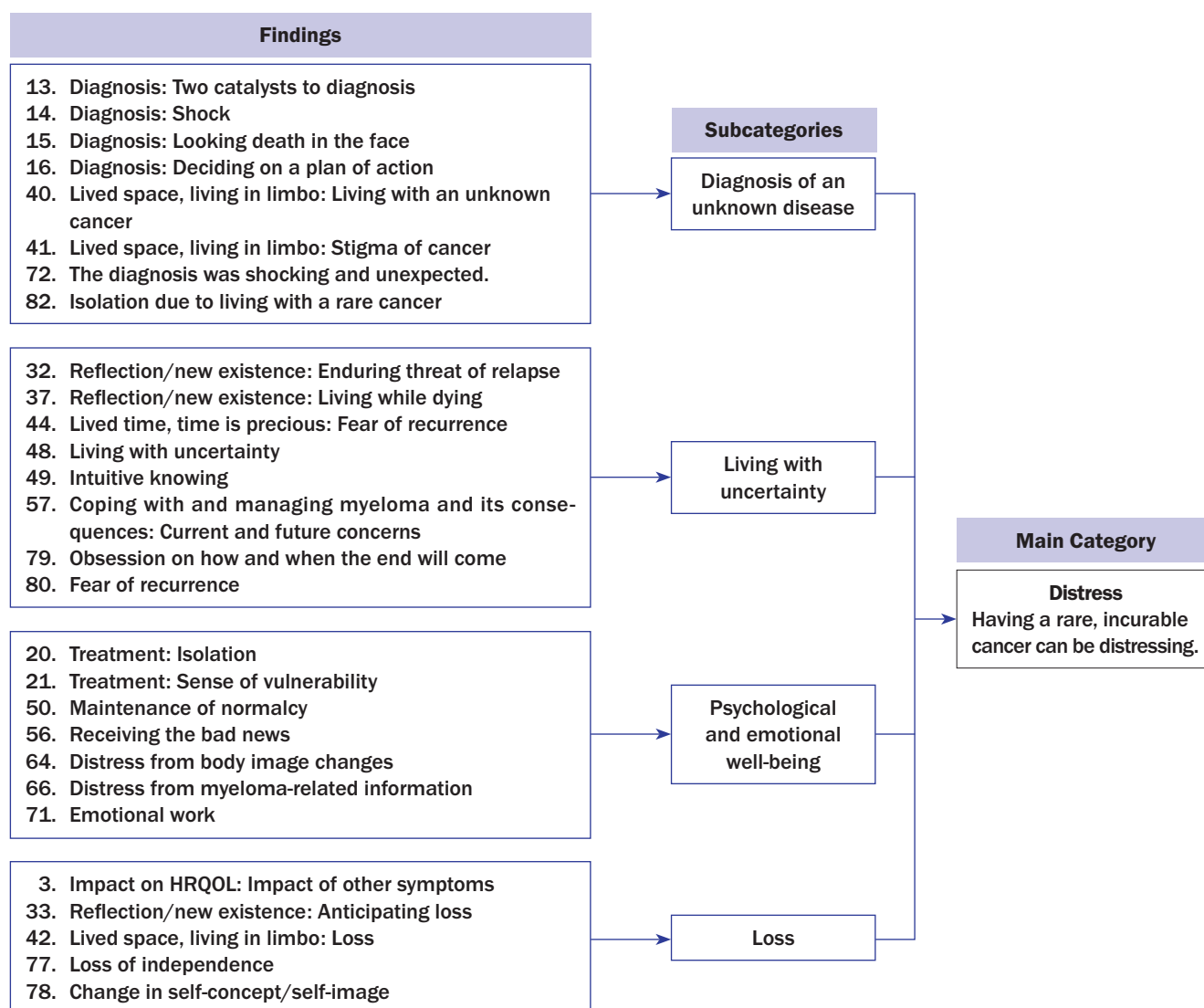
**HRQOL—health-related quality of life**

*Note.* All findings were evaluated as unequivocal except for 63, which was evaluated as credible.

difficult experience that was always at the back of the patients' minds. The patients tried not to let this prospect control their entire existence. Attending routine hospital appointments increased their awareness of the disease and tended to aggravate fear and uncertainty concerning disease progression and the availability of treatment.

**Psychological and emotional well-being:** Myeloma had a substantial impact on patients' well-being. Patients described isolation that was heavily influenced by feelings of being different. This isolation became

more pronounced when simultaneous withdrawal from social activities occurred. Patients felt that they had to be brave and be able to control their emotions, which was not always possible. Having to repeat bad news to family and friends was difficult and stressful. It was of great importance to patients to maintain their normal lives and not let the cancer become the dominant factor. This, however, proved to be a difficult, ongoing task. Hair loss, changes in weight, brittle bones, and other symptoms caused by the disease or the treatment were often a source of distress to the



HRQOL—health-related quality of life

**FIGURE 2. Synthesis of Distress**

patients and made them feel vulnerable. The visible indicators of sickness negatively impacted patients' self-image.

**Loss:** Feelings of loss were related to changes in temporal expectations. These involved perceptions of missing out on or anticipating absence from significant life events with family, and also loss of identity and value. Patients experienced loss of independence and described not being able to do what they used to do, such as working or performing daily household chores. This loss of independence led to changes in self-esteem and made some patients feel useless.

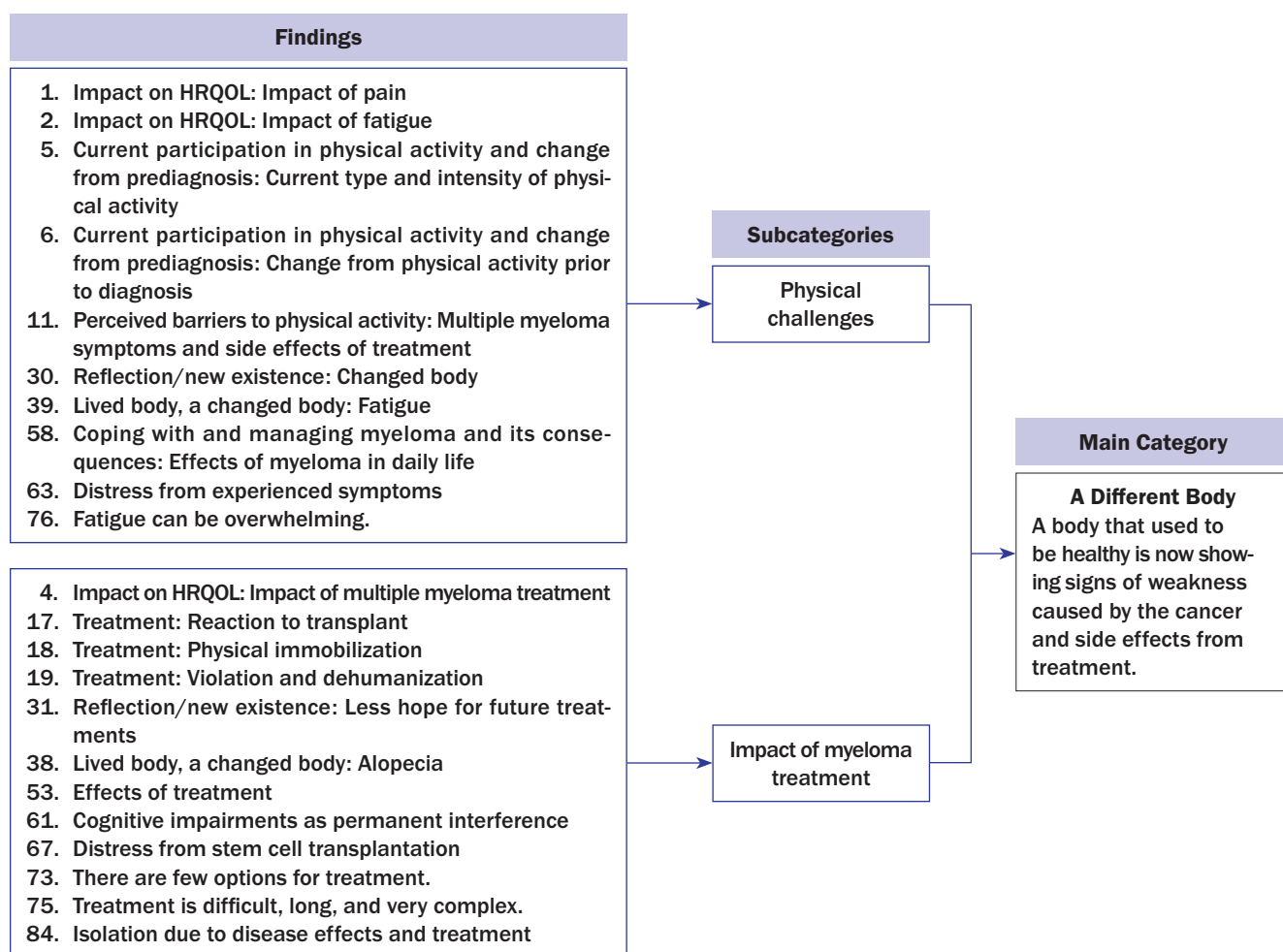
### Synthesis 2: A Different Body

This synthesis is based on 22 findings grouped into two subcategories (see Figure 3).

**Physical challenges:** Fatigue affected patients' ability to participate in life and was described as one of

the main obstacles that caused disability. Although patients were usually physically capable of doing daily chores, their lack of endurance required them to prioritize the situations in which to spend their sparse energy. Some could predict which activities would cause exhaustion, but, for others, unpredictable circumstances, lack of general well-being, or even changes in weather conditions adversely influenced their energy levels. Profound fatigue was a common consequence of treatment.

Pain largely affected patients' lives in the same manner as fatigue. In particular, back pain commonly occurred. However, new pain was also associated with a warning sign of relapse and, therefore, caused additional concern. Collectively, fatigue and pain prevented patients from taking part in desired activities and hindered them physically and socially. Other physical symptoms mentioned were fragile bones,



HRQOL—health-related quality of life

**FIGURE 3. Synthesis of a Different Body**

difficulties with movement, infections, neuropathy, hearing loss, bowel problems, and insomnia.

**Impact of myeloma treatment:** Patients who had undergone different types of treatment (i.e., standard chemotherapy, novel drugs, radiation or high-dose therapy with stem cell transplantation) experienced a wide variety of adverse symptoms. These ranged from marks from IV needles and loss of hair to others such as nausea, neuropathy, and fatigue. Being drained of energy also impaired patients' cognitive function and memory. Although many described their treatment negatively, they felt forced to go through with it because it was their only option. People could not always predict how treatment would affect them; the different treatments and different time points of treatments could vary, from being without complications altogether to having all-encompassing effects on well-being.

Patients were prepared to accept profound adverse side effects if the treatment was effective, but with many relapses, such enthusiasm became difficult to maintain. The perception of freedom became

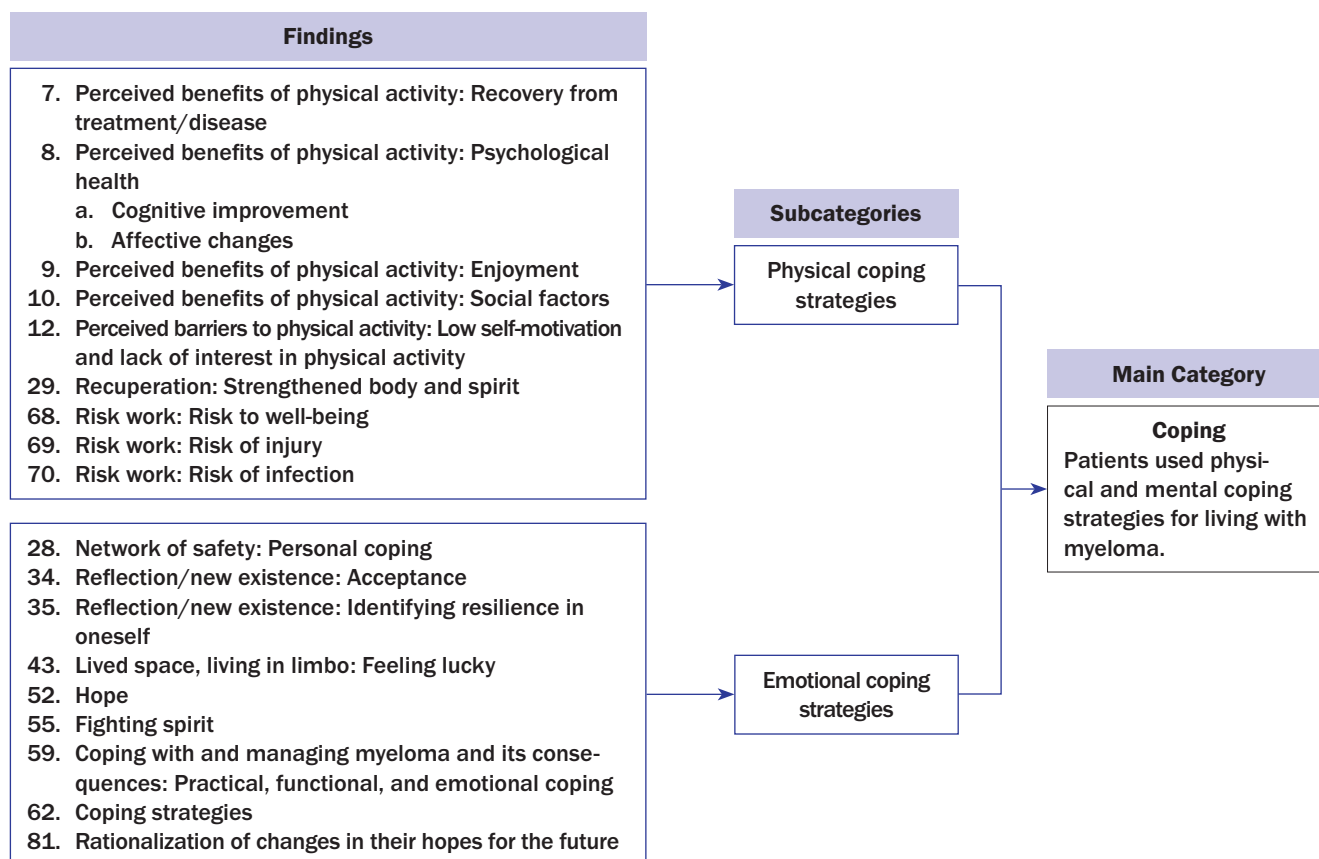
constrained when the treatment affected physical strength, appearance, leisure activities, mental function, and other personal factors. In addition, a weak immune system required patients to discourage friends and family from visiting them to protect themselves from catching contagious common diseases or viruses.

### Synthesis 3: Coping

This synthesis is based on 18 findings grouped into two subcategories (see Figure 4).

**Physical coping strategies:** Patients looked for ways to retain or increase their physical health. They used various approaches, including eating healthier food, drinking more water, and exercising. To prevent infection, some patients boiled their drinking water and avoided situations that would upset the precarious balance of physical well-being. Although exercising was sometimes difficult, it left the patients with a victorious feeling when they succeeded in pushing their physical boundaries and regaining control of their bodies. When recovering from side effects of





**FIGURE 4. Synthesis of Coping**

treatment, physical activity had several benefits, such as improving memory and concentration. In addition, physical activity made them feel better and decreased isolation. Staying on schedule for exercise also gave them a feeling of being in control. However, some people lacked motivation and were dependent on encouragement from others, such as healthcare professionals, to find motivation for activities that they could engage in. Other physical coping strategies focused on minimizing risk of physical harm related to injury caused by peripheral neuropathy and fragile bones. For example, some stopped using public transportation because of the risk of falling and fracturing brittle bones.

**Emotional coping strategies:** Emotional coping strategies were used to stay optimistic and preserve hope in spite of the uncertainty of living with myeloma. Some found this resilience within themselves and focused on enjoying their lives. Some reported feeling fortunate to have a diagnosis and, knowing that time was precious, this helped patients to prioritize and to make the most of their lives. It was important for patients to establish hopes for future experiences, such as having grandchildren. Comparing their own situations to those of others who were less privileged also was a way of realizing that things could be worse.

Although myeloma was not curable, treatment was available.

#### Synthesis 4. Contributions of Other People

This synthesis is based on 16 findings grouped into three subcategories (see Figure 5).

**Family and friends:** The spouses usually provided the most support, both psychologically and with practical chores such as cooking, driving to and from treatment sessions, and so forth. However, other close relationships were also important. Having access to a group of people where it was possible to express feelings freely could provide relief. On the other hand, patients sometimes felt required to shield other people, such as their children, from seeing their suffering.

Although family and friends provided an appreciated network of safety and support, they also caused concern (e.g., repeatedly inquiring about the patient's health and well-being). This increased awareness of their disease at time points when they did not want to contemplate it. Patients also worried about how the increased burden on their families and their future death would affect their loved ones.

**Other people with myeloma/cancer:** Some patients were interested in talking to others with myeloma

about their experience with the disease, but not all had the chance to do so. Because myeloma is usually diagnosed in older adult populations, younger patients did not feel that they had much in common with the majority of other patients, which could lead to feelings of isolation.

**Healthcare professionals:** Patients most frequently described a trusting relationship between themselves and the healthcare professionals involved in their care. However, limited time was available for the patients to talk to healthcare professionals. These time constraints prevented patients from raising questions and discussing their concerns, although they felt the need to do so. In particular, enduring problems that could not be managed well, such as fatigue, pain and mobility, were issues that patients refrained from discussing with professionals because they did not have positive experiences of receiving information that they could transfer into use in their daily life situations. Other sensitive issues impacting the patients' lives were far too rarely discussed with healthcare professionals on the patient's own initiative, such as changes in intimacy and emotional issues. Patients had most contact with healthcare professionals during relapses, and the focus then was on the disease, namely treatment options, monitoring worsening symptoms, and side effects of medication. At times of remission, patients often felt forgotten by the healthcare system.

## Discussion

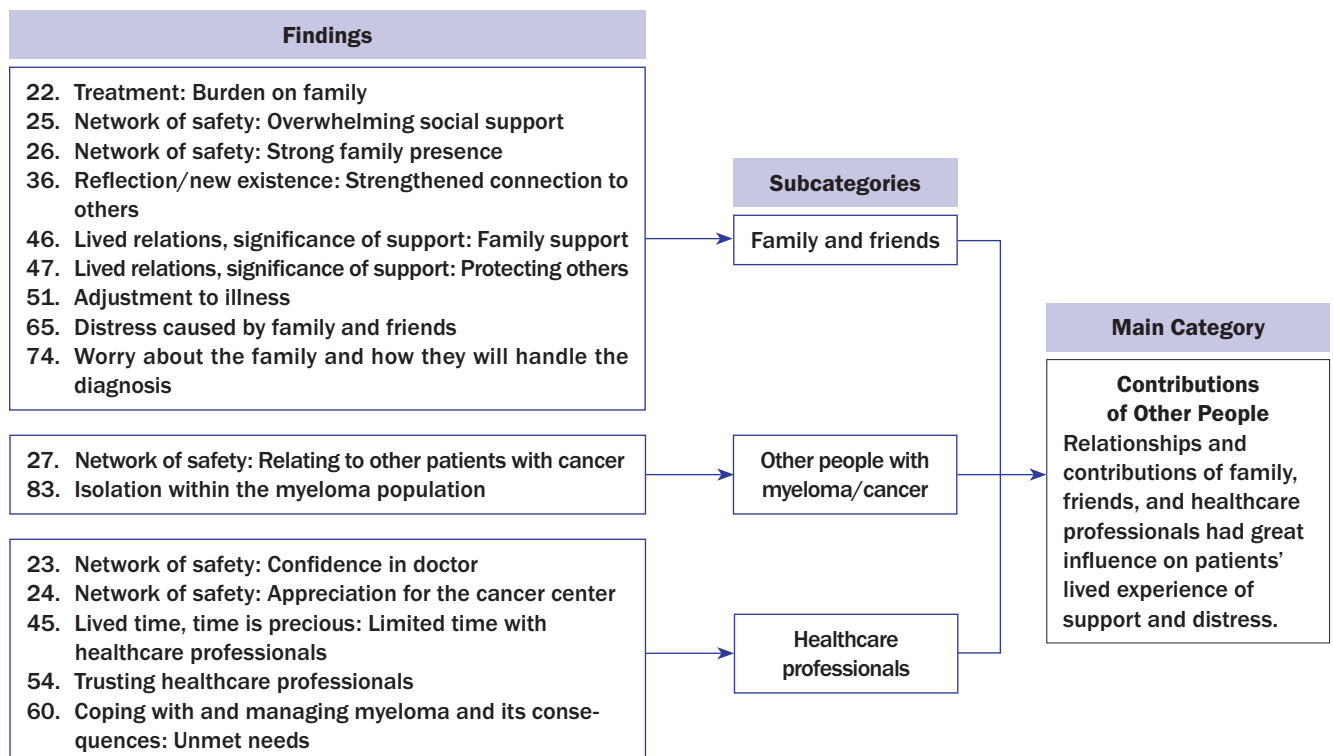
The results from this qualitative review show discrete components in patients' experiences of a life with multiple myeloma. The wide-ranging impact of myeloma on patients' physical, emotional, and social lives that was described, and the illustrations of actions that patients have taken to relieve their symptoms, easily translate into applications in clinical nursing practice. Patients with myeloma need access to ongoing professional support, even in times of remission. The four main categories—distress, a different body, coping, and contributions of other people—might serve as a launchpad for developing new ways of assessing fluctuations and problems of importance associated with myeloma. In the following sections, some major issues within each main category will be discussed, particularly to highlight the clinical implications of the findings in relation to existing knowledge.

### Distress

Distress had the most well-described findings, indicating the importance of healthcare professionals' awareness of the emotional burden that follows a diagnosis of myeloma. NCCN (2016) proposed the following definition of distress:

Distress is a multifactorial unpleasant emotional experience of a psychological (i.e., cognitive, behavioral, emotional), social, and/or spiritual

**FIGURE 5. Synthesis of Contributions of Other People**



nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (p. DIS-2).

Because of the profound impact of distress, it often is viewed as the sixth vital sign (Estes & Karten, 2014). The participants across the 11 studies exhibited a broad spectrum of psychological and emotional symptoms. Most predominant were feelings of loss, sadness, anxiety, uncertainty, and isolation. In many instances, these feelings restricted the participants' lives substantially, and, as such, call for professional attention. Many patients go without the psychosocial care that they require because of under-recognition of their distress. However, patients may also under-report such symptoms because of a fear that others may equate symptoms of distress to mental health problems (NCCN, 2016). A review article by Zabora, BrintzenhofeSzoc, Curbow, Hooker, and Piantadosi (2001) estimated that as many as 43% of patients with cancer are distressed and emphasized that this distress should be evaluated routinely. Nurses have been identified as the most relevant group of healthcare professionals to assess distress in patients with cancer (Abrahamson, 2010), and clinical guidelines recommend routine screening (NCCN, 2016). The distress described in the participants of the included studies further underscores the need to prioritize the identification of distress to enable the initiation of alleviating actions.

### A Different Body

This category provided descriptions of physical symptoms and side effects that patients were challenged with. In congruence with other studies, fatigue and pain were commonly experienced (Coleman et al., 2011; Jordan et al., 2014; Sherman et al., 2004). Through this review, the importance of recognizing the presence of these symptoms and asking patients about them was reinforced, particularly because the symptoms were not always distinguishable despite having a substantial adverse effect on patients' daily lives. Patients generally lacked advice on how to cope with symptoms that were not directly related to worsening in their medical condition and often refrained from seeking advice on their own initiative. This shows that nurses should be proactive in assessing for diverse problems impairing patients' HRQOL. Current HRQOL scales for patients with myeloma address many important symptoms (e.g., bone aches and pain in other areas, side effects of treatment,

## Knowledge Translation

- Individuals with multiple myeloma experience their illness in the categories of distress, a different body, coping, and contribution of other people.
- Healthcare professionals should provide better support during periods of remission and pay more attention to psychosocial, emotional, and personal ramifications.
- New assessment approaches are needed when evaluating the progress, fluctuations, and effectiveness of interventions.

worries) (Boland et al., 2013); however, they do not assess how these symptoms restrict the lived space—activities, connection to other people, possibilities, and well-being of patients. However, the difficulties of providing meaningful solutions to problems without having access to knowledge of *how* symptoms impede patients' experiences is well recognized (Gapstur, 2007). Therefore, healthcare professionals should bear in mind that assessment should go beyond descriptions of symptom strength and consistency to include evaluation of the patients' experience of them (McMillan, Tofthagen, Choe, & Rheingans, 2015). Nursing guidelines predominantly target issues that are related to the management of side effects of treatment and problems that appear with deterioration (Bertolotti et al., 2008; Bilotti et al., 2011). Therefore, development of more all-encompassing assessment and management strategies should be given priority (Lobban & Perkins, 2013).

### Coping

Coping reflects strategies that patients used to maintain some kind of equilibrium in a life with myeloma. The participants said that only a few—if any—previous life experiences had led to more fear than receiving their diagnosis. The diagnosis brought them into proximity to a threat against their own existence, difficult decisions with regard to treatments, and more. When people are diagnosed with myeloma or other forms of cancer, this creates a sudden need to redefine previous priorities and find ways to cope with uncertainty (Hoffman, Lent, & Raque-Bogdan, 2013). Research has shown that such goal reengagement, when it is most successful, can result in psychological satisfaction and positive life changes (Schroevers, Kraaij, & Garnefski, 2011). A concept analysis of learning to live with a chronic disease revealed this as a complex, dynamic, cyclical, and multidimensional adjustment process where the ultimate target was to achieve positive living and to maintain one's own self-identity (Ambrosio et al., 2015). The current authors found that the participants used two

basic kinds of coping strategies, physical and mental. The physical strategies focused on strengthening and safeguarding their vulnerable body, whereas the mental strategies related to finding and keeping up their fighting spirit, discovering inner peace, appreciating the good things in life, and developing hope and faith. This finding has many clinical implications. In their support of patients with myeloma, nurses may function as a catalyst for this adaptive process by helping patients to make explicit the things that they appreciate in life and by helping them to establish new manageable benchmarks.

### Contribution of Other People

In this category, patients described how the relationships and contributions of family, friends, and healthcare professionals greatly influenced their experience of illness. Generally, this support facilitated good experiences. Patients' personal networks helped to relieve them from performing daily activities and habitual chores and provided psychological and emotional support at difficult times. However, patients expressed profound worries, in particular those with more severe disease, that their illness was too much of a burden for their relatives. In the care of patients with myeloma, keeping in mind that patients' challenges affect the caregivers, and vice versa, is important. Because of this interdependent relationship, healthcare professionals should consider the patients and informal caregivers as one unit (McLeod, Tapp, Moules, & Campbell, 2010; Northouse, 2012).

Most patients with myeloma repeatedly mentioned how busy they felt the healthcare professionals were, which hindered patients from communicating how they were feeling. This indicates that nurses should strive to not miss important clues related to what may improve the care of patients with myeloma and their families.

### Limitations

The authors found a lack of qualitative studies with a longitudinal design to enable better descriptions of fluctuations and experiences in various phases of the disease. For instance, only one study explicitly described experiences of long-term survivors with myeloma (Stephens, McKenzie, & Jordens, 2014). Because of this underrepresentation, it remains uncertain whether patients in the end phase of the disease may have other needs and experiences. This issue calls for further research.

Although the authors adhered to a methodologically strict procedure, several limitations must be mentioned. The authors only included studies reported in English and, therefore, more material may be available in other languages. Also, the authors did not

perform manual searches of selected cancer journals. In looking further into patients' needs, it may have been fruitful to access other kinds of literature, for instance, patient helplines and home pages of patients' associations, and to conduct content analysis of this material. However, such analysis would have demanded more resources.

The transferability of the results may be influenced by the selection of patients from the original studies. Of note, the average age of the participants in the review studies was lower than the average age of patients with myeloma in general, and all patients had resources and energy enough to participate in the studies.

### Implications for Nursing

The findings provide an important resource for clinical practice and can be used to improve care for people with myeloma. Although myeloma is chronic in nature, it fluctuates between remissions and relapses. Unsurprisingly, the focus of care has mostly been on patients with myeloma in its more aggressive phase. The evidence provided in this review demonstrates a need for nurses to put further emphasis on implementation of alleviating strategies in the remission stage of myeloma.

The four main categories of distress, a different body, coping, and contributions of other people, cover important items that could be incorporated in an assessment tool suitable for both the active and passive state of myeloma to allow patients to make explicit their own evaluation of their experience. Prevailing HRQOL instruments have not been developed based on qualitative findings and may, therefore, be criticized for paying too little attention to what really matters to patients (Osborne et al., 2012). A scale taking into consideration the qualitative findings could potentially measure the impact of fluctuations, establish particularly vulnerable periods, and assess the effectiveness of alleviating interventions. The scale would be a vital supplement to the application of more conventional screening methods (e.g., the Distress Thermometer [NCCN, 2016]).

Nurses should reach out to patients because patients do not seem to approach healthcare professionals about perceived minor issues impairing their well-being. Nurses could more specifically help patients with focusing on what they *can* do. Better access to specialized nursing care could, for instance, occur through a telephone service (Reid & Porter, 2011), interactive web-based interventions (Kuijpers, Groen, Aaronson, & van Harten, 2013), or homecare support service. These are pragmatic ways to optimize nursing support and to provide



this support in a manner that transfers into use in patients' daily life situations.

## Conclusion

The results of this review show the impact that multiple myeloma has on various aspects of patients' lives, including physically, psychologically, and socially. Nursing care for patients with myeloma should match their experiences and existential needs. The contents within the main categories have a practical value in that they provide nurses with understanding of the challenges that these patients face. This knowledge has direct implications for clinical care provision. In addition, the structure derived from this meta-aggregation provides a useful framework for developing a clinical assessment tool that could help to identify patients in need of alleviating support throughout the continuum of care.

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## Appendix A. Findings and Quotations for Distress

### Diagnosis of an Unknown Disease

#### 13. Diagnosis: Two catalysts to diagnosis

"I had a major bicycle accident where I broke all kinds of bones. I had all these X-rays taken to see if I had broken anything and he noticed what he called a lesion." (Dahan & Auerbach, 2006, p. 369)

#### 15. Diagnosis: Looking death in the face

"It went from a state of shock, then I thought, as they say, 'put your business in order' because you know, I don't know, I didn't know whether I was going to be around the next year or what." (Dahan & Auerbach, 2006, p. 370)

#### 40. Lived space, living in limbo: Living with an unknown cancer

"I was told I had myeloma, now I never heard of myeloma. . . . I did not think it was cancer and I did get a shock when I realized that it was cancer." (Kelly & Dowling, 2011, p. 40)

#### 41. Lived space, living in limbo: Stigma of cancer

"People are not able to talk about it . . . it's this big monster you are carrying." (Kelly & Dowling, 2011, p. 40)

#### 72. The diagnosis was shocking and unexpected.

"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." (Vlossak & Fitch, 2008, p. 142)

#### 82. Isolation due to living with a rare cancer

"My sister was going through breast cancer . . . so the focus was on her because so much is known about that I think. . . . I don't think any of them have any idea about what multiple myeloma is. . . . My sister, she's the one that everybody is more concerned about . . . you know she's got the cancer that everybody knows about." (Wagland et al., 2015, p. 150)

### Living With Uncertainty

#### 32. Reflection/new existence: Enduring threat of relapse

"The problem is that myeloma returns and that it is not curable. So that is in the back of my mind always. . . . It is always in the back of my mind that I know this thing is coming back and the question is when. I think that's what's different maybe about this myeloma maybe than other cancers . . . certain cancers can be cured and myeloma can't. So I think that's a problem." (Dahan & Auerbach, 2006, p. 379)

#### 44. Lived time, time is precious: Fear of recurrence

"I don't think about having myeloma . . . at all except once a month when I go for blood tests . . . when that goes well you are relieved. . . . It's a relief when you don't hear anything bad." (Kelly & Dowling, 2011, p. 41)

#### 48. Living with uncertainty

"I don't really want to have any grand ideas and then my body doesn't live up to it, so I just want to be very open minded and see what happens." (Maher & de Vries, 2011, p. 268)

#### 49. Intuitive knowing

"I knew, I did know, do you know what I mean. I knew by the pain, and so I knew, and Dr. [X] said to me, 'You know it will come back, don't you?' so he'd sown the seed; it was always kind of there, you know?" (Maher & de Vries, 2011, p. 269)

#### 79. Obsession on how and when the end will come

"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 license number of the bus, when we're, you know . . . out of remission." (Vlossak & Fitch, 2008, p. 144)

#### 80. Fear of recurrence

"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?" (Vlossak & Fitch, 2008, p. 144)

### Psychological and Emotional Well-Being

#### 20. Treatment: Isolation

"I don't think I was very communicative. I barely spoke. I think I was upstairs in my room because I was just very weak." (Dahan & Auerbach, 2006, p. 372)

#### 21. Treatment: Sense of vulnerability

"That was the only drawback, when I lost my hair. Now all of these clowns know that I have it. . . . Everybody else could see that something was wrong." (Dahan & Auerbach, 2006, p. 373)

#### 50. Maintenance of normalcy

"I just want to have a normal relationship with [family]. I don't want them ringing me up and asking me how I am and all that kind of stuff. When they phone me I just want to have a normal conversation with them really." (Maher & de Vries, 2011, p. 269)

#### 56. Receiving the bad news

"He said, 'Is there anything you want to say?' and I said, 'No doctor,' because I didn't know what to say and what to do because my heart was so full I couldn't speak and I wanted to cry." (Maher & de Vries, 2011, p. 271)

### Loss

#### 3. Impact on health-related quality of life: Impact of other symptoms

"My wife has become a caretaker per se . . . as far as getting me to doctors' appointments and all that sort of stuff, having to do most of the . . . yard work outside of the house and everything, try and take care of the house, that's put a bigger burden on her. . . . Our children are grown up and gone, so we don't have anybody here except us. So, trying to do those kind of things and physically try to take care of things is definitely affected." (Baz et al., 2015)

#### 33. Reflection/new existence: Anticipating loss

"I think about the plans that I had . . . all the things that I was going to do when I retired. I had plans and all that changed." (Dahan & Auerbach, 2006, p. 379)

#### 42. Lived space, living in limbo: Loss

"I used to walk the road and danced quick steps and all those sort of things. But that is gone now." (Kelly & Dowling, 2011, p. 40)

#### 77. Loss of independence

"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." (Vlossak & Fitch, 2008, p. 144)

#### 78. Change in self-concept/self-image

"[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." (Vlossak & Fitch, 2008, p. 144)

## Appendix B. Findings and Quotations for a Different Body

### Physical Challenges

#### 1. Impact on health-related quality of life: Impact of pain

"I couldn't lift my arms over my head and I still had the pain in my right chest where I knew that the myeloma had started again, so . . . my activities of daily living were pretty influenced by all of that." (Baz et al., 2015, p. 2793)

#### 2. Impact on health-related quality of life: Impact of fatigue

"It got to a point where the reason, one of the main reasons for the disability was fatigue. After I got to work [after] an hour or so I . . . felt like I needed to go sit down, just not tired like somebody that hasn't had any sleep, but body tired, where you physically just don't have a lot of energy. I could do stuff . . . but I just felt real drained when I did." (Baz et al., 2015, p. 2793)

#### 5. Current participation in physical activity and change from prediagnosis: Current type and intensity of physical activity

"So, as I say, I try to walk, I won't say every day but probably five out of seven days a week and I'll definitely go off for about 30 to 60 minutes, depends on the day and the weather and how I'm feeling, what sort of energy I'm at, that sort of level." (Craike et al., 2013, p. 322)

#### 6. Current participation in physical activity and change from prediagnosis: Changes from physical activity prior to diagnosis

"Yeah, look, I wouldn't be doing as intense exercise as I was previously. I physically probably can't do it to the same level that I had. So in terms of quantity it's probably dropped off slightly but there hasn't been a large difference there. It's probably more just the intensity at which I do it." (Craike et al., 2013, p. 323)

#### 11. Perceived barriers to physical activity: Myeloma symptoms and side effects of treatment

"I get tired. I'm ready for bed at 8:30, 9:00 every night, you know . . . as soon as the sun goes down I'm ready for bed and I'll go and jump into bed. . . . So, I don't know whether it's the drugs or whether it's the myeloma. The physicians told me it's probably mainly the drugs that has done it. Hopefully the myeloma is under control at the moment." (Craike et al., 2013, p. 324)

"I've got pains in the back and, look, I'm all right at the moment, touch wood, but you know, pains in the back and hip, one of my elbows and they're just sort of, I don't know, it just grinds you down, I suppose, and makes you come to a stop, or in my case anyway." (Craike et al., 2013)

#### 39. Lived body, a changed body: Fatigue

"I would get very tired in the evening time . . . sometimes I go to bed at 8:00, which would be foreign to me. . . . I never went to bed until 2:00 in the morning." (Kelly & Dowling, 2011, p. 40)

#### 58. Coping with and managing myeloma and its consequences: Effects of myeloma in daily life

"I have problems bending down you know, picking things up off the floor and things like that . . . it's not nice, no I don't like relying on others to do everything for me." (Molassiotis et al., 2011a, p. 104)

#### 76. Fatigue can be overwhelming.

"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." (Vlossak & Fitch, 2008, p. 143)

### Impact of Myeloma Treatment

#### 4. Impact on health-related quality of life: Impact of myeloma treatment

"Well, if they miss the IV, number one, and number two, I always have these marks every time I leave there. I always have marks on my arms. Looks like I'm a drug user." (Baz et al., 2015, p. 2794)

#### 17. Treatment: Reaction to transplant

"The transplant was the only treatment that I have had that was really hard. But it wasn't really that hard for me. . . . I was expecting it to be horrible." (Dahan & Auerbach, 2006, p. 371)

#### 18. Treatment: Physical immobilization

"Only twice did I cry, and that was because I was so exhausted. . . . People don't know what tired is until they have been a cancer patient. . . . When I returned from the stem cell transplant . . . I was at that rock-bottom tired feeling." (Dahan & Auerbach, 2006, p. 372)

#### 19. Treatment: Violation and dehumanization

"I basically lost a year of my life. That is the way I look at it. . . . August until May as lost. All the things that make me who I am, I wasn't during that period. So, it didn't just take away my strength, it took away who I saw myself as a person. You know . . . my hair, my intellect, my reading, my hobbies, all these things." (Dahan & Auerbach, 2006, p. 372)

#### 31. Reflection/new existence: Less hope for future treatments

"I was willing to do everything this first time. I was 49 when this thing started and . . . I didn't want to die. But I really don't want to do this again. So I am not even sure what will happen when this thing returns." (Dahan & Auerbach, 2006, p. 378)

#### 38. Lived body, a changed body: Alopecia

"The only thing that was worrying me was about losing my hair . . . that was the big issue for me in the beginning, because I never cut my hair." (Kelly & Dowling, 2011, p. 40)

#### 53. Effects of treatment

I'm desperately tired, I mean I could roll up now, I'm not saying I'd go asleep; I want to, you know? What I mean, that's the tiredness and I don't know if it is the steroids. I can't assume it is, I can't because I've never known nothing like this, you know, the tiredness and energy sapping, really energy sapping." (Maher & de Vries, 2011, p. 270)

#### 61. Cognitive impairments as permanent interference

"I can hardly remember anything. Honestly, my memory is like a sieve now. I can do things and then I stand there and think what the hell were I doing?" (Potrata et al., 2010, p. 724)

#### 67. Distress from stem cell transplantation

"I couldn't sleep. I still . . . even now, today, I have the problems from it of going to sleep and not, you know, not waking up in the morning even now. How did it look like? I just didn't want to. . . . I didn't want to go to sleep and that was it, you know, I just wanted to be awake all the time and, you know, if anything went wrong, at least I'd be awake to shout out or something." (Potrata et al., 2011, p. 131)

#### 73. There are few options for treatment.

"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." (Vlossak & Fitch, 2008, p. 143)

## Appendix C. Findings and Quotations for Coping

### Physical Coping Strategies

#### 7. Perceived benefits of physical activity: Recovery from treatment/disease

"I think it gives you a more positive outlook if anything. You can get back to normality and you can do things you know." (Craike et al., 2013, p. 323)

#### 8. Perceived benefits of physical activity: Psychological health–Cognitive improvement

"Well I suppose it just keeps you going. Certainly my job is very sedentary and I know that if I don't start the day with some exercise it's harder to concentrate and things like that." (Craike et al., 2013, p. 323)

#### 8. Perceived benefits of physical activity: Psychological health–Affective changes

"Oh, put it this way; I was quite depressed when I was in the house after the stem cells transplant and, of course, after the two VAD chemo. I find myself if I go out and did a bit of walking, I feel a little bit better, so I go from there." (Craike et al., 2013, p. 323)

#### 9. Perceived benefits of physical activity: Enjoyment

"Oh I enjoy it actually—particularly a long walk—as I said before 300 odd kilometers, when you finish a walk like that you feel very . . . as if you've accomplished something really good." (Craike et al., 2013, p. 324)

#### 10. Perceived benefits of physical activity: Social factors

"I'm always better to have done exercise in a group, basketball, netball, all of that. The oncology rehab, going there twice a week and the girls right now we'll go for a walk, now we'll do this, now we'll do that. I need someone to push me a little." (Craike et al., 2013, p. 324)

#### 12. Perceived barriers to physical activity: Low self-motivation and lack of interest in physical activity

"Two things that stop me probably doing a lot of exercise. One is I probably wouldn't be interested in it but the other one . . . I don't have any problem with my heart. I'm sure I could do a bit of jogging or running, but it's no interest to me." (Craike et al., 2013, p. 325)

#### 29. Recuperation: Strengthened body and spirit

"And it seemed like you just kind of get your strength back and then, slowly but surely, you start to feel like you want to move around or get up or do something with yourself . . . I started to get a little more strength and was able to handle each day a little bit better. When you start building that back again, that's when you start feeling better." (Dahan & Auerbach, 2006, p. 377)

#### 68. Risk work: Risk to well-being

"I never drank water before, never did. At first it was hard, but now I drink it. I'll get up in the morning, that's the first thing I've got near the dressing table there and I won't even go for the coffee. Water or green tea, that's all I drink." (Stephens et al., 2014, p. 2804)

#### 69. Risk work: Risk of injury

"I was having problems absolutely terrified I was on the bus because the bus drivers will not wait for you to sit down for a start and if I couldn't get onto a seat where I could hold onto something, I just felt useless. I felt so scared that I was going to fall and break something that I stopped going on the bus." (Stephens et al., 2014, p. 2804)

#### 70. Risk work: Risk of infection

"I boil my water to drink. I guess the reason I did it probably more so because I was at risk of infection." (Stephens et al., 2014, p. 2805)

### Emotional Coping Strategies

#### 28. Network of safety: Personal coping

"I am the type of person that, in the middle of the work day, I will just stop in between meetings and smell the flowers. . . . I have a fairly good attitude of enjoying life as you go along. I like ordinary days . . . so it's what has helped me. This has not been so bad and, like I said, people have it worse." (Dahan & Auerbach, 2006, p. 376)

#### 34. Reflection/new existence: Acceptance

"I have been able to sort of put it in context and deal with the most profound thing that has ever happened to someone. Which is one's impending death. . . . I am not going to plan a birthday party 10 years from now. I probably won't see my children through high school. It's things like that that chokes me up. . . . [But] I have been really blessed with a very rich life." (Dahan & Auerbach, 2006, p. 380)

#### 35. Reflection/new existence: Identifying resilience in oneself

"My relationship with myself is entirely different—I really am an emerging person. Not really different than I was but totally different." (Dahan & Auerbach, 2006, p. 380)

#### 43. Lived space, living in limbo: Feeling lucky

"Sure it can be treated . . . sure what more do you want . . . couldn't it have been an awful lot worse . . . if you have something that at least can be treated, you know, look at all the people that are out there that there is no treatment for . . . you know, thank your lucky stars." (Kelly & Dowling, 2011, p. 40)

#### 52. Hope

"I love my family and I know they love me as well, and I want to be with them for a little longer. I'd like to see my daughters get married and I'd like them to have a baby. I'd like them to have a family you know, and to see the family before I pass away. So that's my quality of life [because] I don't feel like running around the globe anymore." (Maher & de Vries, 2011, p. 270)

#### 55. Fighting spirit

"So I just get on with it; I curse it when it comes to my mind, I swear at it to fuck off 'I didn't invite you in to my body, so piss off.' Yeah, I do. I walk down the street and it comes in my head and I just swear at it to piss off, 'You're not going to stop me doing what I want to do.'" (Maher & de Vries, 2011, p. 271)

#### 62. Coping strategies

"I wanted a short book and, once I stopped being able to read those, I did try magazines and that wasn't satisfying either and I ended up with talking tapes because you can stop those, you know, after half a chapter and pick it up again later on and rewind and, you know, it's not so tiring." (Potrata et al., 2010, p. 725)

#### 81. Rationalization of changes in their hope for the future

"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 traveling if I can, and spending time with my family and my grandchildren and so on." (Vlossak & Fitch, 2008, p. 144)



## Appendix D. Findings and Quotations for Contributions of Other People

### Family and Friends

#### 22. Treatment: Burden on family

"Listen, I tell you, as much as I suffered, [my wife] suffered just as much. It was very hard for her. She also lost a year of her life. She is a very active woman, she plays tennis five times a week, she has an active social life, and basically she was my nurse for a year. So I am sure—it was very, very hard on her. But again, she had a lot of support from her kids and from family and from friends, and I think that is what pulled us all together. She had a very tough year. I think she may have had just as bad a year as I did." (Dahan & Auerbach, 2006, p. 373)

#### 25. Network of safety: Overwhelming social support

"There are ways people can look at you and there are ways that people can look at you. And there are certain people who look at you and they are so awkward and they feel so sorry for you. And there are those who are so caring. You know there are so many people who are just so capable and caring. . . . It's just amazing the capabilities of some of the people who are there with you and you don't have to lie to and say everything is fine." (Dahan & Auerbach, 2006, p. 375)

#### 26. Network of safety: Strong family presence

"[My wife] was—without her I wouldn't have made it. She took care of all the medications, she drove me back and forth to the cancer center almost every day to the hospital. . . . Without her I wouldn't have made it." (Dahan & Auerbach, 2006, p. 375)

#### 36. Reflection/new existence: Strengthened connection to others

"She has been great and I have had a lot more respect for her since this. Because she really rose to it." (Dahan & Auerbach, 2006, p. 380)

#### 46. Lived relations, significance of support: Family support

"My husband was brilliant . . . you really need someone at the time, from the start my husband was very good. I couldn't have got through it without him." (Kelly & Dowling, 2011, p. 41)

#### 47. Lived relations, significance of support: Protecting others

"I was putting [my family] more so ahead of myself and trying to deal with that. I suppose like anything in life there's probably a lot of pretending . . . we pretend an awful lot and you have to, like, put on the good face at home, like, in front of the children." (Kelly & Dowling, 2011, p. 41)

#### 51. Adjustment to illness

"My day-to-day life is OK because I'm happy that I've got my husband living, because he does help me and we do things together. And my daughters are very supportive to me and always want to know how I'm feeling." (Maher & de Vries, 2011, p. 269)

#### 65. Distress caused by family and friends

"Unfortunately, when relatives ask you how are you going on, then it's a reminder again so you have to give them a little update on how you are at [the hospital] and things like, you know, how the figures are going and things like that. When I meet somebody, you know . . . I must admit I . . . it was a bit, you know, just as you were trying to forget, somebody reminds you, so [laughs]. They're well-meaning people of course but you think, oh, right, here we go again [laughs]." (Potrata et al., 2011, p. 130)

#### 74. Worry about the family and how they will handle the diagnosis

"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." (Vlossak & Fitch, 2008, p. 143)

### Other People With Myeloma

#### 27. Network of safety: Relating to other patients with cancer

"I think that people with cancer look at other people with cancer as part of a club of some kind. . . . I remember when I would walk into the cancer center and I would see other people, you know, we all, like, winked at each other . . . if we had the strength. Because we're—it is a club. You know breast cancer, colon cancer, whatever it is. If you have the empathy, you feel some concern for them." (Dahan & Auerbach, 2006, p. 376)

#### 83. Isolation within the myeloma population

"You can relate to them, except that they are all so old." (Wagland et al., 2015, p. 150)

"They are in a different financial position where they . . . don't have to (work), or they are retired." (Wagland et al., 2015, p. 150)

### Healthcare Professionals

#### 23. Network of safety: Confidence in doctor

"Actually it was pretty gruesome and difficult until after I saw Dr. [X] because then he talked about all the possibilities and I was in such good health and I was only in stage II, that there was—while there is no cure necessarily—they were looking to make this a maintainable disease." (Dahan & Auerbach, 2006, p. 374)

#### 24. Network of safety: Appreciation for the cancer center

"I feel that people treat you like a human being and they are so caring and they are really concerned about you and everybody knows you by name. . . . I feel like I have been very supported here." (Dahan & Auerbach, 2006, p. 375)

#### 45. Lived time, time is precious: Limited time with healthcare professionals

"Well, I would love to have asked if I had enough time with the doctor . . . even the nurses . . . they are just so busy . . . but they haven't got time and I think that's a huge minus." (Kelly & Dowling, 2011, p. 41)

#### 54. Trusting healthcare professionals

"How do I fit into this, you know what I mean, so sometimes I think it's better to be more confident with people. You see Dr. [X] say, you need this then that's the end of it. He is the professional he's been at it years; I respect his resolve. Now some of the other run-ins I've had with consultants and that is it's been a bit . . . though they might not mean be harsh, in some respects they can be a bit too harsh." (Maher & de Vries, 2011, p. 271)

#### 60. Coping with and managing myeloma and its consequences: Unmet needs

"Didn't want to burden the doctors with my emotional problems because that wasn't their job . . . their job is to see to the physical problems." (Molassiotis et al., 2011a, p. 105)