


# Interrupted Identities: Autologous Stem Cell Transplant in Patients With Multiple Myeloma

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Sean N Halpin, MA<sup>1</sup> , Michael Konomos, MS, CMI<sup>2</sup>,  
and Ivey Jowers, RN, BSN, OCN, BMTCN<sup>3</sup>

## Abstract

In the current study, we sought to examine whether patients incorporate the identity of a patient receiving autologous stem cell transplant (ASCT) for multiple myeloma (MM) into their daily lives. Multiple myeloma patients receive education before initiating the ASCT treatment process. In this ethnographic study using interpretative phenomenological analysis, we observed pretransplant education visits with 30 MM patients, followed by semistructured interviews in their hospital rooms during transplant. The experience of receiving ASCT for MM required effort by patients to not only maintain their past identity but also establish a new patient identity. Reconciling these 2 identities required deliberate and emotionally draining effort from the patient. Results were organized into 2 overarching themes of social relationships and aesthetics with subthemes for each. Understanding methods MM patients who are receiving ASCT use to negotiate normalcy during treatment may be helpful for developing interventions for alleviating distress during this difficult time.

## Keywords

bone marrow transplant, multiple myeloma, patient experience, stem cell transplant, emotions

## Introduction

Multiple myeloma (MM) is characterized by abnormal plasma cells in the bone marrow, resulting in low blood counts and increased risk of infection (1). Each year, about 20 000 new patients are diagnosed with the disease in the United States (2), making it the second most common hematologic malignancy (1). Although MM remains incurable, advances in treatment have improved the lifespan of patients, especially those receiving autologous stem cell transplant (ASCT) (3,4). Although effective, the process of receiving ASCT is intense, involving demands on the patient and caregiver, yet few studies have explored the experience of people at the time of undergoing ASCT for MM.

Patients often learn about their MM after experiencing symptoms, including anemia, renal problems, bone pain, or fractures resulting from bone lesions (5). An incurable disease diagnosis can be traumatic, causing patients to reconsider their identity. One qualitative synthesis of 84 studies examining the patients' experience of MM indicated that patients felt they had a "different body" post-treatment (6). Studies of other cancers have suggested that patients renegotiate their identity following cancer diagnosis (7–9). These

studies are usually aimed at understanding the post-treatment identity of cancer survivors (10), with MM patients voicing desire to live a "fairly normal life" (11). Ultimately, the new MM patient identity is often defined through feeling distressed (12,13).

Distress includes "multiple unpleasant feelings that may cause problems as you cope with cancer and its treatment," including depression, hopelessness, and fear (14). Individuals with hematologic malignancies, including MM, who experience distress are less compliant, resulting in worse treatment outcomes (15). Yet, distress can be mitigated by social and psychological adaptations to the patient's medical condition.

<sup>1</sup> Department of Education, University of Georgia, Atlanta, GA, the United States

<sup>2</sup> Emory University, School of Medicine, Atlanta, GA, the United States

<sup>3</sup> Emory University, Winship Cancer Institute, Atlanta, GA, the United States

## Corresponding Author:

Sean N Halpin, Department of Education, University of Georgia, 308 River's Crossing, 850 College Station Road, Athens, GA 30602, the United States.  
Email: sean.halpin@uga.edu



Robust social support is especially helpful for keeping up with a complex treatment regimen, along with providing needed psychological support, all of which impact health outcomes (16–19). In addition to assuaging ongoing treatment needs, strong social support can help alleviate fears about the future (20) and lower levels of post-traumatic stress symptoms (21). Yet, patients receiving ASCT who are in relationships with partners who are unhelpful or experience “problematic interactions” had poorer social and emotional functioning (18). Additionally, patients with higher levels of psychological resilience, or the ability to reframe and cope with a traumatic event, have been found to experience less distress following ASCT treatment (22).

Although the treatment process itself often leads to a renegotiation of identity, resulting in high levels of distress, most of this research examines individual’s post-treatment (7–9). This completely ignores the treatment process, which has been identified as the most distressing time for ASCT patients (23,24). In the current study, we sought to examine whether patients incorporate the identity of a patient with MM undergoing ASCT.

## Methodology/Research Design

We examined data from participants taking part in a process evaluation study, Ready for Transplant, aimed at improving education for patients diagnosed with MM who are receiving ASCT (25). The current study represents an exploration into the lived experience of these individuals, with a focus on whether they employed strategies to maintain normalcy during an intensive medical procedure, including the pretransplantation preparatory treatment and the inpatient transplant.

### Data Collection

Methods of data collection included ethnographic observation and interviews with patient–caregiver dyads ( $N = 30$ ). Data were collected by either SNH and MK and reviewed by a nurse navigator who was present. Ethnographic observations took place during the education portion of the patients’ “evaluation day.” The evaluation day consists of activities meant to ensure patients can safely move forward with ASCT, including laboratory workup, electrocardiogram, echocardiogram, pulmonary function testing, radiologic imaging, bone marrow biopsy, meeting with a social worker, and education about all aspects of ASCT provided by a nurse navigator.

Semistructured interviews with patients, or patient–caregiver dyads (who were observed previously), took place in the patient’s hospital room on the patients second day of admission. The interview guide was based on the Information-Motivation-Behavioral Skills model (26), beginning with a broad overview of the patient’s experience learning about their MM diagnosis along with how their emotions when diagnosed, followed by their experience preparing for ASCT. The interview was followed by a brief

demographic form and the single-item literacy screener (27). Health-related quality of life (HRQoL) was assessed using the 7-item Functional Assessment of Cancer Therapy answered on a 5-point Likert type scale (possible range = 0–28), with high scores indicating better HRQoL (28). Additional 2 ethnographic interviews took place with each patient during their 2-week hospitalization. Patients were recruited by nurses in the clinic, and no patients declined. All observations and interviews were audio-recorded.

### Data Analysis

The researchers analyzed the data using Interpretative Phenomenological Analysis (IPA) (29–31). In the first phase of analysis, the researchers summarized text with unstructured notes, organized in tables. Next, researchers viewed the abstracted tables and all text files, seeking patterns or inconsistencies both within and between patients. Researchers evaluated the meaning of repeated language given the context and the individual responses, including how patients made sense of a phenomenon and how they presented themselves. In the second phase of analysis, emergent themes were noted throughout the data. Last, a list of superordinate themes was constructed by clustering themes and the links between them. Themes were linked with the patient’s language to illustrate their interpretations, ensuring the emergent themes were grounded in the patients’ accounts of their experience (32).

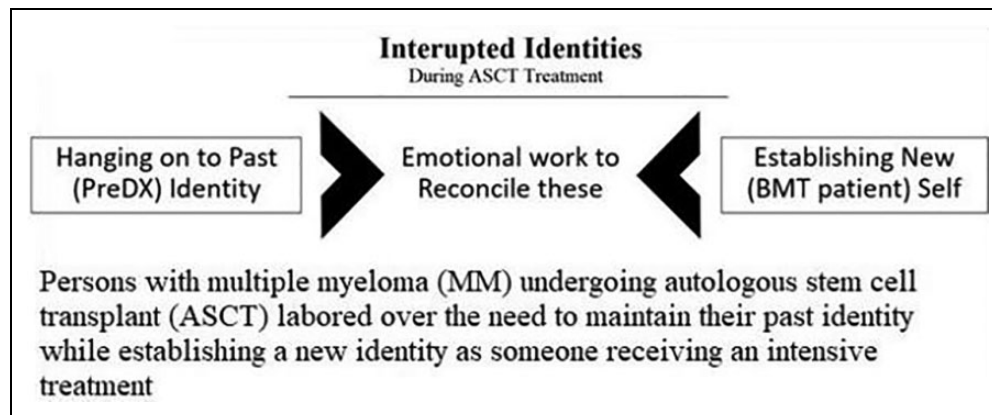
Analytical rigor was assured through triangulation and reflexivity (33). As the purpose of IPA is to examine the patients’ lived experiences, researcher’s reflected on their worldview and how this might influence their interpretation of the data (33,34). Data were interpreted and examined by all authors. Team members included a gerontologist with expertise in qualitative methods, a medical illustrator, and a nurse with content expertise in ASCT. All data management was completed in NVivo version 12.3 (QSR International Pty, Ltd, London). The current study was reviewed and approved by the Emory University and University of Georgia institutional review board (IRB# PROJECT00000748), informed consent was deemed not necessary. To ensure anonymity, pseudonyms are used for all patients.

## Findings

The experience of receiving ASCT for MM required effort by patients to maintain their past identity, as well as to establish a new patient identity (Figure 1). Results were organized into 2 overarching themes of social relationships and aesthetics, with subthemes for each. Patient demographics are described in Table 1.

### Social Relationships

Social relationships provided an avenue for maintaining feelings of normalcy, as well as critical support for



**Figure 1.** Persons with multiple myeloma (MM).

**Table 1.** Demographics.

Characteristics	Total sample, n = 30
Median age (range), years	61 (41-72)
Male, n (%)	18 (60)
Race, n (%)	
Asian	1 (3)
Black	12 (40)
White	17 (57)
FACT-G7, median (range)	15 (10-21)
Health literacy question	
Never	15 (50)
Rarely	4 (13)
Sometimes	8 (27)
Often	2 (7)
Always	1 (3)
Caregiver age (range), years	59 (43-73)
Female, n (%)	25 (83)
Informal care provider, n (%)	
Child	6 (20)
Parent	2 (7)
Spouse	22 (74)

Abbreviations: : FACT-G7, Functional Assessment of Cancer Therapy (possible scores = 0-28); Health literacy question, How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

navigating the ASCT process in terms of both logistical (eg, transportation) and emotional needs. Patients navigated these sometimes-conflicting demands through 2 subthemes: (1) spouse/child/friend to caregiver and (2) concerned friends and family.

**Spouse/child/friend to caregiver.** All patients had a spouse, child, or friend who served as their caregiver, providing a range of assistance including transportation, managing the patient's schedule, providing medical care at home (eg, administering subcutaneous injections), and emotional support (eg, encouragement). Importantly, this new caregiver position often resulted in a shifting of roles from egalitarian (eg, spouse) or subordinate (eg, child) to one where the patient was now reliant on the caregiver. Patients used a

variety of strategies for dealing with this transition of roles, ranging from embracing to dismissing the new roles.

Arnold, a 50-year-old black male, exemplifies a patient who negotiated the role change in an egalitarian way. During the evaluation day visit, he and his wife carefully listened to the education they were receiving, with his wife speaking up to correct possible miscommunications between the nurse coordinator and patient, rather than to redirect the conversation to her own needs. For example, at one point, the patient mumbled that he previously had pain in his stomach when giving bortezomib subcutaneous injections. The nurse replied, "we can get you something," to which the wife clarified, "oh no, he is asking if he can take the 10 mg of hydrocodone he is prescribed to take every 12 hours." Later, when interviewed in his hospital room, Arnold gushed that he and his wife were "closer than ever" due to the illness. They spent their wedding anniversary at the hospital, but both felt that the time together was very valuable.

Alternatively, Shane, a 71-year-old white male who was especially distressed about ASCT, relegated all caregiving duties to his daughter. A potent example of this occurred during the evaluation visit, as highlighted in the following field note excerpt: "The mother pulled a pill from a bottle and started looking at her watch. She showed the pill to her daughter—then looked at her husband's watch and looked down at the pill again." Finally, the daughter interrupted [the nurse], "excuse me, I am sorry, is that pill for nausea?" The mother confirmed that the pill was for nausea and it was the scheduled time for Shane to take it. When interviewed in his hospital room several weeks later, Shane was asked specifics about how his treatment had gone. "I don't know," he replied, "my daughter takes care of that."

**Concerned friends and family.** Patients relied heavily on the friends and family to provide a connection to their pre-ASCT lives, by keeping up with everyday stories that might otherwise have been taken for granted. Additionally, patients relied on these same friends and family for emotional support, but often simultaneously felt overwhelmed by the need to provide "updates" on their health status.

Marilyn represents a patient who navigated this push and pull from friends and family. A 71-year-old, white female, Marilyn, and her husband, both exuded a welcoming and nonjudgmental calmness that likely contributed to their robust social network. Like many patients, Marilyn expressed thankfulness in the personal testimonials she received from friends and family who had themselves received ASCT for MM. These same friends warned her of the exhaustion that could follow from explaining her health status to an endless flow of friends. She heeded their recommendation and joined an online community meant to help patients stay connected with their friends and family.

That is where people are getting information, that are praying for you, that are interested but you are not having to have these exhausting exchanges. And the other thing that I did this last time is I thought, I don't want to be, I don't want to be writing stuff over these next couple of weeks, so I've asked people to answer kind of an open-ended question. Just what is the most beautiful thing that you saw today. So, they write every day and they tell me something beautiful.

Magdalena, a 70-year-old black female, felt both encouraged and emotionally drained by a constant barrage of family independently researching and advising on her treatment. The stress caused by her having to manage the information that multiple family members barged her with was evident. "They research and research and research," Magdalena said, and ultimately while she was grateful, she explained to her grandson, "God decides these things, you know."

### **Aesthetics**

Patients reflected on their appearance as a means for outwardly projecting a sense of normalcy while simultaneously negotiating their changing environment (eg, inpatient) and body. Regarding aesthetics, we found 2 subthemes included clothing and body changes.

**Clothing.** Patients described the clothing they wore helped them "feel normal" during a tumultuous time in their lives, despite sometimes not aligning with recommendations from hospital staff. This was especially true during the "evaluation day," where patients were recommended to wear comfortable clothing due to the long day, visiting many different areas of the hospital and undergoing uncomfortable procedures. Patients routinely showed up to these visits with clothing that expressed their personality, including pressed slacks, fashionable prints, and jewelry. Alternatively, staff did recommend that patients wear "street clothing" rather than hospital gowns, while inpatient in the hospital, advice that patients followed dutifully.

Gerry, a 64-year-old male, was emblematic of a patient who carefully selected his clothing while in the hospital. He and his wife planned a vacation to Hawaii before his treatment, but their plans derailed after he fell and broke his hip.

During his hospital stay, he wore a Magnum PI replica print Hawaiian shirt. Gerry joked that the broken hip, and the resultant infection due to bed sores during recovery, was his vacation, "at least I can pretend like I am in Hawaii while I have to be in here," he joked, pointing to his shirt.

Susan, a 71-year-old retired white female, came to her evaluation day visit in attire she described as "glamorous", as described in the following field note excerpt: "She wore a white, quarter length shirt with lace around her shoulder, black capris, and open toed shoes that revealed her freshly painted pink toenails." Susan cried throughout the visit, and about half-way through she cut the visit short and stating, "This is just too much information, I'm done now, no more information." She returned a few days later to receive the additional information. Later, in the hospital, she wore a black and white China-patterned gown, explaining, "I just want to feel normal."

**Body changes.** The bodily changes patients experienced were a constant reminder of their interrupted identity as a patient undergoing ASCT, including the central venous catheter that dangled from their chest, brushing against clothing, and uncomfortably rubbing against seat belts. Others perseverated about the expected bodily changes related to treatment, especially the anticipated hair loss.

William, a 64-year-old single black male, is symbolic of a patient who fretted over the central venous catheter; a foreign piece of technology which he equated to a reminder of his mortality, despite being no stranger to wearable technology. During the evaluation day visit, he pulled down the neck of his shirt to reveal the quarter sized port protruding from his skin from which he had previously received chemotherapy. Despite this experience with a port, he was incredulous about the central venous catheter, asking in a pained voice, "and it's going to be hanging out?" He elaborated that the catheter was a "monster" and the "scariest part" of his treatment.

The expected loss of hair was especially worrisome for most patients. Julia, a 69-year-old black female, focused all her questions on what to expect regarding her hair. The nurse navigator suggested she could write a prescription for a "hair prosthesis," which assuaged the patient. During 2 ethnographic interviews in the patient's hospital room, spread out over 1 week, Julia wore a dark green head covering. Likewise, Jeff, a 53-year-old white male with wavy brown hair, fretted to the nurse, "my mane is my pride . . . but it will grow back, right?" Alternately, some patients embraced this expected change during their hospital stay. Eugene, for example, used the provided hospital clippers to shave either side of his head, leaving a top strip. He announced emphatically, "if I have to go through this, I thought I might as well have a mohawk, it is going to fall out anyways."

### **Discussion**

Throughout the ASCT process, patients labored over the need to maintain their past identity while simultaneously

establishing a new identity as someone receiving an intensive treatment. Indeed, previous studies on MM survivors found that the concerns over remission and relapse required “Emotion work aimed to manage the feelings of self” (35). This indicates that patients struggle with the fact that MM is incurable, and they often have concerns over whether they can handle going through treatment again (36), along with concerns over dealing with one’s own mortality (6).

Although social support is important throughout the disease process, previous studies suggest that a strong social support network is most critical for combating distress while MM patients are in the hospital receiving transplant (24). Within the context of incurable illness, caregivers who gauge responsiveness without infantilizing, or treating someone as a child, are more likely to adapt to meet changing needs (37,38). Likewise, in the current study, patients typically voiced less distress when they had caregivers who acted in a supporting role, allowing for the patient to remain centered in their own care. Caregivers in the current study used varying techniques, which highlighted their ability to (or to not) responsively adjust to the patients changing needs including allowing the patient to lead conversations but stepping in and asking clarifying questions when needed.

Patients adopted various aesthetic strategies to either embrace or conceal bodily changes. The decisions patients made surrounding these physical reminders existed within a context of varying levels of distress. One study found that MM patients felt that hair loss symbolized the loss of one’s identity (39). Studies of other cancer populations have identified similar patterns as outlined in the current study. For example, women receiving chemotherapy for breast cancer tend to experience distress from unwanted hair loss (40). These women often choose to conceal their new “cancer” identity with prosthetic hair pieces. Interestingly, even those who did not lose their hair still experienced extreme distress over the possibility. Others have found that cancer survivors may carefully choose clothing to “conceal” their cancer diagnosis (41). The current study expanded on these previous findings, showing that patients experienced distress while negotiating normality by using strategies such as concealment through clothing choice while undergoing ASCT.

Although our findings of how patients negotiated their new normalcy regarding social support and aesthetics, we were unable to account for premorbid factors. For example, it is unclear whether patients’ relationships with their caregivers followed preexisting patterns of communication (eg, egalitarian vs infantilization) or if these patterns of communication developed while dealing with treatment. Additionally, feelings of distress were qualitatively implied and not examined in a way that could highlight the degree of distress across patients.

## Conclusion

Understanding methods MM patients receiving ASCT use to negotiate normalcy during treatment may be helpful for

developing interventions for alleviating distress during this difficult time. Medical professionals should inquire into patients’ social networks in order to make more tailored recommendations.

## Authors’ Note

All data management was completed in NVivo version 12.3 (QSR International Pty, Ltd, London). The current study was reviewed and approved by the state Emory University and University of Georgia institutional review board (IRB# PROJECT00000748), informed consent was deemed not necessary. To ensure anonymity, pseudonyms are used for all patients.

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## ORCID iD

Sean N Halpin, MA  <https://orcid.org/0000-0001-5624-6083>

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### **Author Biographies**

**Sean N Halpin** is a gerontological researcher. He is interested in research methods for addressing chronic conditions in older adults.

**Michael Konomos** is the team leader of the Visual Medical Education group at Emory University School of Medicine.

**Ivey Jowers** is a bone marrow transplant nurse navigator at the Winship Cancer Institute.