Care Coordination

Overcoming barriers to improve outcomes for patients with hematologic malignancies in rural settings

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BACKGROUND: Most patients with cancer experience financial, emotional, and logistical barriers to care that significantly affect their adherence to and successful completion of treatment. However, patients with hematologic malignancies, particularly those who live in rural settings, must also contend with additional challenges.

OBJECTIVES: This article aims to synthesize the literature about barriers to timely access to care and to coordination of care for patients with hematologic malignancies, particularly those in rural settings, as well as identify strategies to improve cancer care delivery for those patients.

METHODS: A search of the literature from 2008–2018 pertaining to rural health disparities for patients with hematologic malignancies, along with ways to overcome these disparities, was conducted.

FINDINGS: Patients with hematologic malignancies, particularly those who reside in rural settings, face complex barriers to care. These barriers cause emotional and physical distress. A team approach to care coordination that is focused on eliminating these barriers and improving outcomes is needed.

HEMATOLOGIC MALIGNANCIES INCLUDE A DIVERSE GROUP OF DISEASES of the bone marrow and immune system, such as leukemia, lymphoma, and multiple myeloma (Lobb et al., 2009; McGrath, 2015; Olsen, 2013). Because the treatments for hematologic malignancies are directly targeted at cancer cells in the bone marrow, lymphatic system, and immune system, the production of normal cells (red blood cells, platelets, neutrophils) is markedly affected (Lobb et al., 2009; Walter et al., 2013). These intense treatments, coupled with the disease process itself, have a profound impact on immune function, leading to increased risk for prolonged neutropenia and severe infection and to the need for supportive care, including red cell and platelet transfusions (Lobb et al., 2009). The number and overall length of treatments, plus the frequent travel required for transfusion support, may be debilitating to patients and impair their quality of life; they may also experience emotional or psychological distress from missed work and time away from family (Langbecker, Ekberg, Yates, Chan, & Chan, 2016; Lobb et al., 2009). Patients who live in rural settings face profound challenges related to care coordination. Specific barriers include issues related to transportation (e.g., distance to travel for care, reliability of car), low health literacy, the lack of a reliable caregiver, and financial concerns. Management of patients with hematologic malignancies is unique and complex, and intense coordination of care is required to ensure that patients have the best possible outcomes.

The purpose of this article is to review the complex needs of patients with hematologic malignancies, particularly those who live in rural settings, with a focus on barriers to care and to the completion of therapy. In addition, this article identifies challenges for patients treated in rural settings. Strategies for successful coordination of care will be suggested and demonstrated through a case study.

Hematologic Malignancies

The most common hematologic malignancy, non-Hodgkin lymphoma, represents 4% of all new cancer cases in the United States and has a 71% five-year survival rate (National Cancer Institute [NCI], n.d.). Non-Hodgkin lymphoma is generated from lymphocytes (T cells or B cells) within the lymphatic system and is divided into aggressive and indolent subtypes; the subtype and presenting symptoms guide the oncologist’s plan for treatment (NCI, n.d.; Olsen, 2013).

Leukemia is a cancer of the blood cells that is classified into subgroups based on its aggressiveness and the type of cells affected. For instance,
lymphocytic leukemia is a cancer of the lymphocytes, and myeloid leukemia is a cancer of the myeloblasts (NCI, n.d.). Leukemia represents about 4% of all new cancer cases and has a 61% five-year survival rate (NCI, n.d.). It is slightly more common in men than in women and is most frequently diagnosed in patients aged 65–74 years (NCI, n.d.). Chronic forms of leukemia (chronic myeloid leukemia and chronic lymphocytic leukemia) generally have a better prognosis than acute forms of leukemia (acute myeloid leukemia and acute lymphocytic leukemia). Treatment for leukemia depends on classification of the individual’s disease, but standard treatment is often chemotherapy and/or stem cell transplantation (NCI, n.d.; Olsen, 2013; Walter et al., 2013).

Multiple myeloma is characterized by an overproduction of abnormal proteins and antibodies, which is caused by a high proliferation of plasma cells within the bone marrow (NCI, n.d.). Symptoms of myeloma are related to excessive growth of the plasma cells and their direct effect on the bones, the kidneys, and red blood cell production; they may include anemia; pathologic fractures; and elevated calcium, protein, or creatinine (Olsen, 2013). Myeloma represents 2% of all new cancer cases and has a 51% five-year survival rate (NCI, n.d.). Treatment generally consists of steroid therapy, chemotherapy, radiation therapy, and autologous stem cell transplantation (NCI, n.d.; Olsen, 2013).

Hodgkin lymphoma, a cancer of the lymphatic system, represents about 1% of all new cancer cases and has an 87% five-year survival rate. The disease is more common in young adults (NCI, n.d.) and consists of two major types: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma. Symptoms at presentation often include enlargement of the lymph nodes and/or fever, weight loss, and night sweats (NCI, n.d.). Treatment for Hodgkin lymphoma predominantly involves chemotherapy and radiation therapy but may include stem cell transplantation in patients with relapsed or refractory disease (NCI, n.d.; Olsen, 2013).

Methods
A search of online databases (i.e., ProQuest Nursing and Allied Health Database, CINAHL<sup>®</sup> Complete, and MEDLINE<sup>®</sup>) was initiated to determine the complexities of cancer care for patients with hematologic malignancies in the United States, specifically those in rural settings. Keywords used were healthcare access, healthcare barriers, rural settings, cancer, care coordination, and hematologic cancers. The literature searched was from 2008–2018.

A total of 27 studies were identified through the literature search. Information regarding disparities among patients with cancer in rural settings was overwhelmingly prevalent; however, findings revealed little information specific to patients with hematologic malignancies and those living in rural settings. These findings demonstrated a need to synthesize and present findings on these topics to better understand the unique needs of, as well as identify ways to overcome barriers to care to improve outcomes for, this population.

Patient Needs and Barriers to Care
For patients with cancer, several barriers affect the cancer experience and influence overall outcomes. In the United States, about 9% of adults aged 19–64 years are uninsured, and 28% are considered to be underinsured (Barnett & Berchick, 2017; Collins, Gunja, & Doty, 2017). These uninsured and underinsured patients are more likely to present with advanced stage disease and experience barriers in receiving standard care; this is attributable to the cost of care and/or their lack of access to preventive care or prescribed treatments (Walker et al., 2014; Zafar et al., 2013).

Patients can experience financial distress even with the support of health insurance. In fact, patients with cancer with insurance frequently have out-of-pocket costs and copayments for medications or procedures that are higher than those of patients with other conditions (Walker et al., 2014; Zafar et al., 2013). The sudden onset of many hematologic malignancies requires urgent treatment and extended hospitalization. When patients are unable to work or maintain income or insurance coverage, financial stress and family distress increases. Many patients and their family members resort to working longer hours, selling belongings, and decreasing spending on leisure activities or daily expenses to pay for needed cancer treatments (McGrath, 2015; McNulty & Khera, 2015; Zafar et al., 2013). Caregivers may alternate responsibilities to reduce role strain, and many continue working to support the patient and the patient’s needs (Lobb et al., 2009).

Transportation is considered one of the major barriers to healthcare access and treatment compliance among patients with cancer. Access to a vehicle improves access to medical care.
and adherence to appointments, whereas distance from care is considered to be a limiting factor, meaning that it increases the likelihood that adherence will be a concern (Syed, Gerber, & Sharp, 2013). Geographic location and socioeconomic status contribute to transportation barriers in the form of access to financial resources (vehicle, gas for vehicle) and caregiver availability (Butow et al., 2012; McGrath, 2015; Zafar et al., 2013). A patient’s inability to come in for a scheduled clinic visit causes delays in care and missed treatments, which, ultimately, contributes to poorer outcomes (Syed et al., 2013).

**Barriers for Patients in Rural Settings**

Although barriers to care exist for all patients, patients who live in rural or remote settings have unique needs and disparities that are often more complex than those of patients in urban settings (Butow et al., 2012; McGrath, 2015). According to the 2017 American Society of Clinical Oncology Practice Census Survey, about 20% of U.S. residents live in rural settings, whereas only 9% of oncology practices are considered to be rural (Charlton, Schlichting, Chioreso, Ward, & Vikas, 2015; Kirkwood et al., 2018). Patients who live in rural settings often live more than 60 minutes from their oncologists, which equates to traveling as much as three times longer to receive care than patients who live in urban settings (Charlton et al., 2015). Lower health literacy of rural patients is a major predictor of health-related quality of life and outcomes; at least 25% of patients in rural settings have an unmet educational need (Butow et al., 2012; Charlton et al., 2015; Halverson et al., 2015; McGrath, 2015).

Patients in rural settings frequently report problems with transportation and cite it as a major barrier to adherence to the prescribed treatment plan (Kamimura, Panahi, Ahmmad, Pye, & Ashby, 2018; Syed et al., 2013). For many patients, the intensity of treatments and the blend of inpatient and outpatient/supportive care results in physical relocation to receive timely, coordinated care (McGrath, 2015). Reasons for relocation include the need for intensive chemotherapy, administration of blood products, and access to a bone marrow transplantation center or oncology specialists (e.g., hematologic, surgical, or radiation oncologists) (McGrath, 2015).

Although some patients in rural settings may have a local oncologist, significant barriers still exist for those with hematologic cancers. Patients needing inpatient induction or maintenance chemotherapy for acute leukemia or high-grade lymphoma must travel to the nearest tertiary treatment facility because many rural hospitals do not have the capacity to care for this population (Charlton et al., 2015; Halloway, 2015; McGrath, 2015). A patient needing specialized oncology care requiring inpatient hospitalization and aggressive chemotherapy or transfusion support often has a higher acuity than the staff of a rural hospital or a rural hospital itself can support. Patients with hematologic malignancies often require blood count checks and transfusions at least three times weekly (Walker et al., 2014). In some rural outpatient oncology clinics, access to on-site blood products for same-day administration is often not available, which forces patients to come to larger centers for care. In addition, many rural centers may only provide oncology care on certain days each week, limiting access for any acute needs that may arise (McGrath, 2015; Walker et al., 2014).

**Strategies to Improve Access to Care and Care Coordination**

Improving coordination of and access to care is key to ensuring the best outcomes for patients. Having a team of dedicated healthcare professionals (e.g., nurses, social workers, case managers, financial counselors) is imperative. All patients and family members should have a network of providers and established processes in place that focus on identifying potential or actual barriers to care, as well as ways to overcome those barriers.

One approach to the provision of such care is the use of navigators. Depending on the organization, a navigator may be a social worker or a case manager, a volunteer, or a nurse navigator. Navigators assess patient needs, identify and eliminate barriers to care, and link patients to local, regional, and national resources. Navigator roles vary but can include the provision of education and psychosocial support, as well as...
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assistance with social, financial, or logistical issues that may arise during treatment (Rogers, 2016). For patients with hematologic cancers, navigators coordinate inpatient and outpatient chemotherapy administration and supportive care, and they ensure patient compliance with prescribed regimens (Holloway, 2015). Navigators may help to coordinate patient appointments, including adjusting schedules, collaborating with multiple providers or offices, and organizing visits to make sure that care is clustered or arranged close to home to minimize or eliminate travel concerns (Holloway, 2015).

However, having a formal navigator is not imperative for coordination of care for this population. More importantly, each care setting must design a process that is unique, considering its resources and challenges, and designate an interprofessional oncology care team that is dedicated to identifying and eliminating barriers to care for this population.

To improve access to care delivery in rural settings, teleconferencing may be incorporated into the patient’s care plan. However, limitations with teleconferencing and virtual tumor boards (in which the interprofessional oncology care team uses videoconferencing to share patient cases and formulate a plan of care) still exist (e.g., Internet availability, costs of providing advanced technology, logistical concerns) (Charlton et al., 2015). The team should consider coordinating care so that it easily transitions from the inpatient to the outpatient setting. For patients with acute leukemia, this transition can improve quality of life, as well as decrease the risk for nosocomial infections and minimize the healthcare costs associated with a prolonged hospitalization (Vaughn, Buckley, & Walter, 2016; Walter et al., 2013). High acuity of patients with hematologic malignancies, distance from a suitable outpatient facility, or inability to arrange a reliable caregiver may preclude success of this strategy (Vaughn et al., 2016).

In addition, the patient’s team can connect patients and family members to national and local resources. For patients with hematologic malignancies, organizations like the American Cancer Society and the Leukemia and Lymphoma Society can assist with gas cards, lodging, and copayments for prescription medication, insurance, and treatment. Figure 1 provides additional resources related to care of patients with cancer, particularly those living in rural settings. Reaching out to community partners, including local nonprofit organizations and churches, for possible financial or logistical assistance (e.g., lodging support, volunteer drivers for appointments or treatments, assistance with gas fees) is another option. In some locations, the American Cancer Society’s Hope Lodge may provide lodging during treatment to alleviate the burden of travel (American Cancer Society, n.d.). The oncology clinic or care team may also develop partnerships with local hotels or volunteer agencies to provide lodging at a discounted rate.

Many pharmaceutical companies have resources to help patients with reimbursement of travel expenses or financial assistance with chemotherapy or supportive care medications (U.S. Centers for Medicare and Medicaid Services, n.d.). Table 1 provides suggested interventions to help overcome some of the most common barriers to care for patients who live in rural settings.

The following case study highlights a plan of care for a patient who lives in a rural location. The care plan is possible because of care coordination and the efforts of the patient’s interprofessional oncology care team.

**Case Study**

M.S. is a 50-year-old small-business owner living on a rural island. For several weeks, he noticed more fatigue than usual, as well as a decreased appetite and an unintentional 10-pound weight loss. He scheduled an appointment with his primary care provider, who performed a comprehensive blood count. M.S. was referred to a hematologist for pancytopenia and abnormal cells on his peripheral blood smear. A bone marrow biopsy confirmed the diagnosis of acute myeloid leukemia.

M.S. was admitted to a tertiary medical center for induction chemotherapy and hospitalized for four weeks during marrow recovery and transfusion support. After subsequent cycles of consolidation chemotherapy, he was referred for a bone marrow transplantation evaluation and was accepted as a transplantation candidate. He successfully underwent the transplantation and continues in follow-up care.

M.S. lived in a rural area that was accessible only by ferry. On this small island with a population of about 950 people, resources were limited. Access to a tertiary medical center with staff and resources capable of caring for patients with acute leukemia was about four and a half hours away, including ferry and car travel. Just one primary care provider was on the island, and residents

**TABLE 1. INTERVENTIONS TO IMPROVE BARRIERS TO CARE FOR PATIENTS LIVING IN RURAL SETTINGS**

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**Note.** Based on information from Charlton et al., 2015; Holloway, 2015; McGrath, 2015; Rogers, 2016; Syed et al., 2013; Walter et al., 2013.
had no direct access to an emergency room. M.S. experienced several episodes of febrile neutropenia during treatment, which required his being airlifted to the tertiary center for timely care and rapid initiation of IV antibiotics.

M.S.’s diagnosis of leukemia created a substantial emotional and psychosocial burden, and M.S. and his family experienced extreme distress. Because of M.S.’s sudden inability to work, financial concerns persisted, including fear of loss of income and insurance. M.S.’s family experienced caregiver role strain, and his siblings alternated taking time away from work to assist him. The distance M.S. had to travel to receive care created additional stress and barriers that seemed insurmountable.

M.S. was assigned a team of providers, including nurses, a hematologist/oncologist, a dietitian, and a social worker, that helped to coordinate his care. Collaboration with his primary care provider ensured that he underwent close surveillance in between chemotherapy cycles. Although M.S.’s primary care provider was agreeable to the oncology team’s helping with care, several barriers remained. Reports from routine laboratory work were not posted until 24–48 hours after the draw, causing delays in recognition of abnormal values that necessitated immediate transfusions or interventions. In addition, because there was not an oncology office or regional medical center on the island, M.S. was not able to receive transfusion support close to home and needed to travel to his hematologist/oncologist’s office for care. The office was 135 miles away, but the travel time was about four and a half hours because transportation via ferry was required. The distance M.S. had to travel for care was considered by his care team when appointments were scheduled. If possible, appointments were clustered to help ease the burden of travel. If M.S. was going to miss the last ferry to his island when hospitalized for care, the team arranged for his overnight accommodations at the Hope Lodge.

For his bone marrow transplantation, M.S. and his family had to travel more than six hours to the transplantation center. A team approach was necessary to ensure that M.S. was able to successfully receive the transplantation (coordinating appointments, arranging overnight stays with consideration of travel times). Open communication was established between M.S.’s primary oncology team and the bone marrow transplantation team. M.S. was able to receive pretransplantation testing and laboratory work closer to home to minimize the need for additional travel.

Availability of pharmacy needs and delivery of medication was challenging. For example, M.S. was prescribed Neupogen® (filgrastim) for self-injection. Proper storage of the medication included refrigeration (36°F–46°F) and protection from sunlight; overnight delivery from the pharmacy to M.S.’s home was necessary to ensure stability of the drug (Amgen, 2018). The pharmacy responsible for shipping the package had to coordinate with the ferry and the shipping company; this prevented timely delivery in several cases.

M.S. had access to over-the-counter medications at his local grocery store; however, any prescriptions for acute needs (e.g., antibiotics, antiemetics) had to be filled at the nearest retail pharmacy, which was an hour away. A proactive approach was necessary to ensure that M.S. received his medications in a timely manner. M.S. filled many medications at his primary oncologist’s office, and efforts were made to arrange for larger supplies (a 90-day supply versus a 30-day supply) to decrease the frequency of his visits to the retail pharmacy.

**Implications for Nursing**

Nurses are in a unique position to assess, identify, and improve timely access to care and positively affect the overall experience of the patient with cancer. They provide frontline contact and serve as a liaison for patients who are facing barriers to care (McGrath, 2015). Nurses may be involved in patient care through navigator or coordinator roles, which allow for an individualized approach to each patient’s case. In addition, nurses and nurse leaders often conduct community assessments to better understand the needs of the population that they serve. Once these needs are understood, the team can work to develop partnerships aimed at improving community well-being and access to individualized resources.

A team approach is necessary to ensure that care is coordinated based on the patient’s or family’s preferences while considering any limitations created by geographical isolation and/or availability of resources. Nurses advocate for patients and families to proactively identify potential and current concerns and address any needs that may arise. They are also involved in education related to medication adherence and symptom management, and they address emotional needs through therapeutic communication. Nursing knowledge and understanding of the complexities of the healthcare system help drive outreach initiatives and influence healthcare delivery (McGrath, 2015).

**Conclusion**

Patients with cancer often face financial, logistical, and emotional barriers to care that may negatively affect their adherence to and completion of treatment. Patients with hematologic malignancies must also contend with complex treatments and the need to relocate to receive inpatient chemotherapy or tertiary medical care. In addition, patients living in rural areas are affected by the distance they must travel to receive care and the burden of this travel; they also experience significant healthcare disparities and
limited resources. Having a team that is committed to identifying any such barriers, improving access to care, linking patients with resources, and coordinating care closer to home improves patient satisfaction, adherence, and overall outcomes.

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REFERENCES


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