Informal Caregivers’ Knowledge and Practice of Caring for Neutropenic Patients

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Cooperation of informal caregivers on neutropenic patient care is very important. This descriptive study includes interviews with 100 informal caregivers of inpatients who became neutropenic at least two days previously. Data were collected through face-to-face interviews on informal caregivers’ knowledge and practice of caring for patients with neutropenia. The authors found that some rules, such as washing hands and attention to personal cleaning, were known and practiced; other rules, such as having a bath every other day, were less well known.

At a Glance
- Caregivers should be provided with regular training and standard education programs.
- Informal caregivers should be observed when engaged in their routines to assess whether their practice is appropriate in neutropenic patient caring, and nurses should check whether or not their recommendations are being applied and ensure any deficiencies are addressed.
- The verbal instruction provided by nurses for caregivers does not include enough information about care for neutropenic patients.

Background

Neutropenic individuals are at increased risk of infection for several reasons. First, the immune system is compromised, either as a result of disease, such as acute leukemia, or as a result of treatment, such as chemotherapy or immunosuppression following transplantation. Second, bacterial translocation from the gut to the lymph nodes, bloodstream, liver, and spleen has been shown to increase in neutropenic patients (Lyman, Abella, & Pettengell, 2014). Finally, antibiotic use, antacids, protein malnutrition, and bowel obstruction have been shown to lead to bacterial overgrowth in patients with cancer (Siegel, Rhinehart, Jackson, & Chiarello, 2007). Complications also result in chemotherapy dose reductions or treatment delays, which may compromise clinical outcomes (Lyman et al., 2011). Neutropenia-related complications place a substantial burden on the healthcare system, with inpatient cost estimates ranging from $7,100–$19,100 per neutropenia-related hospitalization (Stokes et al., 2009). Neutropenic patient care is an important issue for managing complications that are linked with neutropenia and shortening of neutropenia duration. Guidelines about neutropenic patient care from the Centers for Disease Control and Prevention (CDC), the European Oncology Nursing Society, the Oncology Nursing Society, the National Institute for Health and Care Excellence (2012), and others have been published (Eggenberger, Krumwiede, Meiers, Bliesner, & Earle, 2004; Marrs, 2006; Nirenberg et al., 2006; Tomblyn et al., 2009). Based on these guidelines, suggestions on neutropenic patient care are included in Figure 1.

Although guidelines indicate that informal caregivers have an important role in preventing infections in neutropenic patients, few studies exist about knowledge and practice of neutropenic patient care by informal caregivers. This study aimed to describe the knowledge and practices of informal caregivers on neutropenic patient care.

Methods

This descriptive study was conducted in the Department of Hematology/Medical Oncology at a university hospital at Gülhane Military Medical Academy in Ankara, Turkey, from December 2012 to July 2013.
When patients were determined to be neutropenic, a doctor or nurse verbally informed patients and informal caregivers about the guidelines for neutropenic care. In addition, patients were placed in a single room that had a “neutropenic patient” sign on the door. This study included interviews with informal caregivers of inpatients who were deemed neutropenic two days previously. Data were collected in face-to-face interviews using a form that was developed as a result of literature review by researchers. The data collection form included introductory questions about the informal caregivers’ characteristics and application of the rules of neutropenic patient care.

The authors obtained written consent from the ethics committee of the hospital. Informed consent was obtained from participants prior to the study.

Results

One-hundred informal caregivers participated in the study. The mean age of the caregivers was 43 years (SD = 13). Of the informal caregivers, 67% were women, 82% were married, and 54% possessed a high school degree or above (see Table 1). Informal caregivers’ knowledge of neutropenic patient care rules and results about the practice of these rules are presented in Table 2. All informal caregivers indicated that they had knowledge of and practiced rules of patient care, including “washing hands,” “separation of dirty objects from clean ones,” “attention to personal cleaning of informal caregivers,” and “following infection symptoms and control.” The least well-known and practiced rules of informal caregivers included “cleaning patient’s armpits and groin area two times per day,” “having a bath every other day with consideration of patient's blood rates,” and “not feeding patient with thin-skinned fruits, but, if given, they should be peeled.”

Discussion

The guidelines published by the CDC and other professional organizations stated that the most important rule in neutropenic patient care is hand washing (CDC, 2015; Nirenberg et al., 2006; Siegel et al., 2017; Tomblyn et al., 2009). In the current study, all informal caregivers stated that they were aware of the hand-washing rule and that they followed it. This can be considered a positive result in the prevention of infections, which constitute the greatest threat to neutropenic patients. Precautions, such as “cleaning and drying of regions that are considered high risk for the development of infections, such as skin folds like the axilla and inguinal region” and “bathing of the patient at least twice a week,” are the least known and the least practiced procedures among caregivers, which can be considered an area for further education. Healthcare-associated pathogens can be recovered not only from infected or draining wounds, but also from frequently colonized areas in normal and intact patient skin. The perineal or inguinal areas tend to be the most heavily affected, but the axilla, trunk, and upper extremities (including the hands) are also frequently colonized (Pittet et al., 2006). Healthcare providers should investigate why those rules were the least known and least performed by caregivers.

The natural microorganisms that exist in the environment that contaminate food, can be grouped as microbial flora (Ozkaya & Cömert, 2008). As a result of the suppression of the immune system in neutropenic patients, the contamination of food with such flora may lead to infections (Lund & O’Brien, 2011). In addition, patients with cancer often have a reduced food intake and, under certain circumstances, a malabsorption of nutrients, which may lead to the development of nutritional deficiencies (Garófolo, 2013). In the hospital in which the current study was conducted, caregivers are allowed to bring safe food prepared under appropriate conditions.

### Table 1. Sociodemographic Characteristics of Informal Caregivers (N = 100)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>X</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>42.95</td>
<td>12.86</td>
<td>18–81</td>
</tr>
</tbody>
</table>

- **Gender**
  - Female: 67
  - Male: 33

- **Marital status**
  - Married: 82
  - Single or widowed: 18

- **Education level**
  - Illiterate: 7
  - Primary education: 39
  - High school degree or above: 54

- **Employment status**
  - Unemployed: 67
  - Employed: 33

- **Place of residence**
  - Province: 53
  - County: 33
  - Village or town: 14

- **Relationship with the patient**
  - Mother, father, brother, or sister: 36
  - Spouse: 27
  - Child: 24
  - Other: 13

- **Receiving aid for patient care**
  - Yes: 65
  - No: 35

- **Knowledge about disease and side effects**
  - Yes: 100
  - No: –

- **Informed that patients are neutropenic**
  - Yes: 100
  - No: –

- **Told about rules of patient care**
  - Yes: 100
  - No: –
into the facility from outside, providing patients with food they like and want to decrease problems related to feeding and the loss of appetite that develops in patients as a result of diseases and treatments. In that situation, informal caregivers must ensure the careful preparation and presentation of the food. In the current study, most of the caregivers responded that they knew the rules related to the preparation and presentation of food and followed those rules as part of the patient care they provided. In contrast to these positive results, “disposing of cooked food that has remained outside the refrigerator for more than two hours” and “not serving patients fruits with thin skins; if the patient wants to eat them, serving them only after washing the fruit and peeling” were the least known practices among the informal caregivers. The topics related to the feeding of patients should be emphasized in detail during the education of caregivers.

Disturbances in the oral mucosa and the development of mucositis in neutropenic patients are common conditions that can

### TABLE 2. Knowledge and Practice of Informal Caregivers on Rules That Must Be Followed for Neutropenic Patient Care (N = 100)

<table>
<thead>
<tr>
<th>Rule</th>
<th>Knowledge of Rule</th>
<th>Frequency of Application of Rule</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Bed sheets must be changed when they get dirty.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Caregivers must be careful about self-cleaning.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Caregivers must wash their hands after using the toilet.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Caregivers must wash their hands before and after meals.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Caregivers must wear masks while they stay with the patient.</td>
<td>94</td>
<td>1</td>
</tr>
<tr>
<td>Catheter must be protected while the patient is having a bath.</td>
<td>96</td>
<td>–</td>
</tr>
<tr>
<td>Dirty objects must be preserved in separate bags.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Food must not be left exposed in room.</td>
<td>94</td>
<td>–</td>
</tr>
<tr>
<td>Hands must be washed before and after patient care.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Hands must be washed before and after preparing meal for the patient.</td>
<td>100</td>
<td>–</td>
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<tr>
<td>If caregivers meet with visitors, contagious disease carriers must not be accepted.</td>
<td>95</td>
<td>–</td>
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<tr>
<td>Living plants must not be kept in the room.</td>
<td>94</td>
<td>–</td>
</tr>
<tr>
<td>Meals must be well cooked.</td>
<td>98</td>
<td>–</td>
</tr>
<tr>
<td>Minimum number of objects must be kept in room, and these must be clean.</td>
<td>91</td>
<td>–</td>
</tr>
<tr>
<td>Neutropenic patients’ caregivers must not be in contact with other infected patients and their caregivers.</td>
<td>92</td>
<td>–</td>
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<tr>
<td>The patient’s armpits, groin area, and skinfold areas must be cleaned with soap and water and dried well two times per day.</td>
<td>41</td>
<td>–</td>
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<tr>
<td>The patient must be enabled to have a bath every other day by taking into consideration blood rates.</td>
<td>64</td>
<td>–</td>
</tr>
<tr>
<td>The patient must not be fed with thin-skinned fruits. If a patient wants fruit, it must be washed and peeled.</td>
<td>65</td>
<td>–</td>
</tr>
<tr>
<td>The patient must be provided with mouthwash at least three times per day.</td>
<td>96</td>
<td>–</td>
</tr>
<tr>
<td>Probable infection symptoms must be followed and checked.</td>
<td>100</td>
<td>–</td>
</tr>
<tr>
<td>Food should not be taken outside the hospital.</td>
<td>97</td>
<td>–</td>
</tr>
<tr>
<td>Visitors must not be accepted to the patient’s ward.</td>
<td>95</td>
<td>–</td>
</tr>
<tr>
<td>Water, milk, and fruit juice must be stored in disposable, pocket-sized containers that patients can consume at a single time. Remaining amounts must not be given to patients and must be disposed.</td>
<td>96</td>
<td>–</td>
</tr>
</tbody>
</table>
affect the quality of life and the treatment processes of patients (van der Velden, Herbers, Netea, & Blijlevens, 2014). Evidence-based studies have demonstrated that mucositis may be prevented or minimized with proper oral hygiene (Lalla et al., 2014; McGuire, Correa, Johnson, & Wienie ndts, 2006). In the hospital in which the current study was conducted, mouthwash, along with instructions for its correct use, is given to the patient and the informal caregiver by the charge nurse to address the issue of oral hygiene. The mouthwash is kept in the patient’s room, and the patient is encouraged to use mouthwash with tooth brushing and flossing at least three times per day. Although most of the caregivers reported that they were aware of the need for oral hygiene at least three times per day, about one-third of them reported that they used mouthwash irregularly. The verbal instructions provided by nurses on the need for oral hygiene increased the knowledge of the informal caregivers; however, some deficiencies were identified in the application of this knowledge. Verbal instruction alone is not sufficient for the education of the patient and the informal caregivers, so nurses should check whether or not their recommendations are being applied and ensure that any deficiencies are addressed.

In Turkish culture, friends and family commonly visit patients and their relatives at home and in the hospital during times of illness to share their sorrow and offer support. Although such visits are made with good intentions, they may not always be in the best interest of the patient because of the potential for infection. Family members will be aware of the potential dangers of such visits, but they will be disinclined to relate the situation to visitors or refuse them access to the patient. In the current study, most of the informal caregivers reported that they did not accept visitors. In addition to the sensitivity of the caregivers related to this subject, raising awareness of the issue and highlighting the hospital rules and procedures may be effective in dissuading visitors.

Conclusion

Although all or most of the informal caregivers in the current study were aware of and performed a great number of the rules associated with the care of neutropenic patients, some rules were less well known and performed less by the caregivers. Standard education programs should be launched for caregivers because they play an important role in patient care and should be provided with regular training. In addition, informal caregivers should be observed when engaging in their routines, and any deficiencies that are identified should be addressed under the supervision of nurses.

References


