Empowering Individuals to Self-Manage Chemotherapy Side Effects

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Providing concise, consistent, and individually relevant patient education is critical. At one institution, patients and families attended a chemotherapy education class consisting of an 11-minute DVD and an oncology nurse–facilitated group discussion. Postclass and eight-week follow-up surveys assessing understanding of treatment side effects, self-care management, and confidence in managing side effects were administered. Quantitative and qualitative data suggested the DVD and oncology nurse–facilitated group discussion provided consistent information, flexibility, and expert knowledge in empowering patients and families to self-manage chemotherapy side effects.

Educating patients about chemotherapy and its side effects is standard practice throughout most cancer centers and is recognized as an Oncology Nursing Society standard of care (Neuss et al., 2013). Instructing patients on side-effect management and behavioral strategies can decrease health-related distress, increase coping, reduce anxiety, and promote self-care (Kinnane & Thompson, 2008; Lorig et al., 1999; Williams & Schreier, 2005).

Although information about chemotherapy is widely accepted as being useful for patients with cancer, differences exist in location, timing, and who provides the information (Gonzalez & Stepan, 2006; Lock & Willson, 2002; Piredda et al., 2008). Three opportunities are present at the authors’ institution for patients to learn about their chemotherapy treatment. One is the outpatient chemotherapy unit, where the patient is provided one-on-one instruction on the day of treatment by an outpatient chemotherapy infusion nurse at any time during their infusion therapy appointment. Patients also may receive one-on-one instruction from an inpatient hematology/oncology nurse on the day of treatment. In addition, the patient may receive information from the Cancer Education Center (CEC) in the form of a biweekly class provided by oncology nurse educators in the outpatient setting.

Before the development of the oncology nurse–led class featuring a DVD and group discussion, oncology nurse educators within the CEC had been providing a general chemotherapy class entitled What You Need to Know About Chemotherapy. The original class delivery method consisted of a 60–80 minute presentation. Supplemental National Cancer Institute and American Cancer Society brochures regarding chemotherapy and side-effect management were available. Although teaching materials were available for staff to use, no coordinated curriculum existed.

Noting the differences in educators’ teaching styles, a task force of oncology nurses, educators, physicians, and patient advocates was established to develop a single, evidence-based chemotherapy curriculum focusing on key messages and self-care strategies for side effects. The topics addressed included managing blood counts (red blood cells, white blood cells, and platelets), mouth sores, constipation, diarrhea, nausea and vomiting, taste and appetite changes, fatigue, peripheral neuropathy, hair loss, sexual relationships, emotional changes, and the resources available at the cancer center. Those topics served as content for developing the 11-minute DVD using lecture slides with voiceover. Health literacy and media experts from the departments of patient education and media support services at the Mayo Clinic were involved in the production of the DVD. Those departments were responsible for ensuring institutional standards were achieved.

Specific goals for the new curriculum included (a) identifying key messages; (b) providing consistent, evidence-based information; (c) providing opportunities for reinforcement; (d) ensuring health literacy needs were met; and (e) facilitating discussion and involvement of patients and caregivers (e.g., family, significant others, friends). The aim of the study was to receive feedback from individuals regarding the coordinated curriculum and whether it met the goals.
Methods

The study was approved by the institutional review board of the Mayo Clinic in Rochester, MN. All patients and caregivers attending the biweekly chemotherapy education class were offered an opportunity to enroll in the survey study. The oncology nurse–led class used the 11-minute Managing chemotherapy side effects DVD as the platform to facilitate group discussion and address individual needs. That format allowed for the greatest amount of flexibility in meeting the identified goals by ensuring consistency of key messages, providing an opportunity for reinforcement, and addressing health literacy needs regardless of where or when the instruction occurred. Free copies of the DVD were provided to class participants regardless of study participation.

The nurse educators informed attendees of the optional study survey at the beginning of class. However, informed consent and survey instruction and completion were obtained at the end of the session. Participants also were mailed a follow-up survey eight weeks later to assess the use of the presented self-care strategies.

Measures included researcher-generated questions assessing participants’ self-reported understanding of chemotherapy side effects and confidence in managing side effects following the class. Example questions included, “Did watching the chemotherapy video and talking to the nurse increase your understanding of how to manage chemotherapy side effects?” and, “Did watching the video and talking to the nurse increase your motivation to use strategies (e.g., drinking water, exercising, hand washing, mouth care) outlined in the education session?” Questions were asked about the individual’s satisfaction and use of the DVD presentation as a reinforcement tool. Similarly, participants were asked about their satisfaction with receiving consistent information from the healthcare team. Finally, the survey asked participants to identify whether the information provided affected their anxiety about receiving chemotherapy. The questions were pilot tested with about 10 patients prior to the formal survey collection. Descriptive statistics (e.g., mean, standard deviation) were used to summarize the collected data using SPSS®, version 15.0.

Results

Eighty-one participants (66 patients with cancer and 15 caregivers, all aged 18 years or older) enrolled in the study and completed an immediate postclass survey. Of those, 42 (35 patients and 7 caregivers) completed an eight-week follow-up survey, either through the mail or by phone. Thirty-one (47%) of the patients already began chemotherapy treatment prior to attending the chemotherapy class.

The information presented in the DVD and the group discussions led by the oncology nurse increased self-reported understanding of side effects (65 patients [98%], 15 caregivers [100%]) and how to manage side effects (64 patients [97%], 15 caregivers [100%]). The DVD and the oncology nurse facilitation increased motivation to use self-management strategies (65 patients [98%], 15 caregivers [100%]), and increased confidence to manage side effects among participants (58 patients [88%], 15 caregivers [100%]).

Forty-eight people (73%) listed new or different behaviors they planned to use to manage chemotherapy side effects. The themes of the participants’ responses included dietary changes (e.g., increasing fluid intake; eating small, frequent meals), increasing physical activity, communicating with healthcare professionals (e.g., make certain to talk with a doctor to understand exactly what he or she wants), and psychological coping strategies (e.g., be gentle, have a positive attitude).

At the eight-week follow-up, 24 patients (69%) reported having used strategies presented in the class. Qualitative data revealed a range of coping strategies in the areas of diet (e.g., smaller, more frequent meals; avoid certain foods), mouth care (e.g., soda solution for sore mouth, rinse mouth often), and medication options. Even those who began chemotherapy treatment prior to taking the class reported that they found value in the class. Noted themes included, “Reminded me of things that I have to do,” and, “You can’t learn enough about chemo.”

When asked what they liked best about the DVD and the interaction with the oncology nurse, participants stated that they valued the opportunity to ask questions about the treatment and the group format that provided the opportunity to discuss with other individuals their experiences in various stages of treatment.

The qualities of the oncology nurses are important. The participants reported that they liked being able to ask questions to the nursing staff and felt the nursing staff was knowledgeable and had positive interpersonal skills.

Discussion

The DVD and the facilitated discussion by an oncology nurse helped participants know what to expect with the side effects of chemotherapy and to learn self-care strategies while not increasing their fears about the treatment process. That confirms similar findings suggesting that information about chemotherapy is helpful for patients (Kinnane & Thompson, 2008). The DVD also brought up topics that the participants wanted to discuss. These findings remained consistent and relevant from baseline to follow-up assessments.

The authors assumed that the best timing for information about chemotherapy treatment to be provided is prior to the beginning of treatment. However, the authors’ results suggest that even those who had already begun treatment (n = 31, 47%) found benefit from the class. Most reported feeling empowered by the information and that it was helpful to review self-care techniques. In addition, having individuals in different stages of treatment appeared to provide an opportunity for group learning.

A major theme in the qualitative data suggests the oncology nurse discussion facilitator was viewed as a content expert, which was important to the participants (e.g., “It was good to have such a knowledgeable person relate this. She inspired confidence.”). The DVD helped provide consistent information during the class and covered the most common evidence-based side-effect management
strategies related to chemotherapy treatment.

Several limitations and strengths existed within this study. One of the limitations was the use of a convenience sample. The chemotherapy class was optional and individuals who chose to attend the class came seeking information and were motivated to learn. The class size also varied from session to session, resulting in different class dynamics. In addition, the authors did not evaluate the benefits of the DVD and nurse separately, so benefits cannot be attributed to either individually. Although the questionnaire was based on other patient surveys, it was not validated.

Strengths also were present in the design and implementation of the DVD, class, and survey. Having a multidisciplinary team develop the content of the DVD and use of evidence-based practice guidelines were important. The DVD format was cost efficient and allowed for distribution to patients and caregivers free of charge. Data suggested the value of the class was stable over time given the results from the eight-week follow-up survey. Finally, the DVD and class curriculum met all of the goals originally identified.

Conclusion

The DVD was an excellent introductory and reinforcement tool for providing key, low health literacy, evidence-based information about chemotherapy side-effect management. When shown within the context of a course led by an oncology nurse educator and facilitated group discussion, the ultimate combination of consistent information and flexibility were provided. An important finding of this study is that individuals genuinely value the expertise of the oncology nurse and group support from others receiving treatment.

References


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