Patient Education: The Cornerstone of Successful Oral Chemotherapy Treatment

Kristine Hartigan, RN, BA, OCN®

The number of patients receiving oral chemotherapy agents and the intensity of these agents are predicted to increase in the near future. Oral chemotherapy offers many potential advantages, such as patient convenience, elimination of the need for IV access, and the ability to achieve sustained drug levels. One drawback, however, is the likelihood that oral chemotherapy treatment distances patients from their healthcare providers and, therefore, changes the way patients are monitored. Opportunities for professional assessment may be fewer and farther between than assessments of patients who receive IV chemotherapy (Birner, 2003).

Patient education, therefore, becomes the cornerstone of successful oral chemotherapy treatment. Effective patient teaching about oral chemotherapy promotes patient safety, optimal dosing, adherence to the treatment plan, accurate assessment of side effects and toxicities, and implementation of self-care measures.

Medication Adherence

The issue of medication adherence is a minor one with regard to IV chemotherapy but a potentially large one with oral chemotherapy administration. In many cases, the degree of patient adherence with an oral chemotherapy regimen is related directly to the degree of treatment success. Nonadherence to a prescribed oral chemotherapy treatment plan generally will result in ineffective or inadequate treatment.

Adherence issues are not well understood, and the specific process of medication adherence is difficult to measure with any degree of accuracy. However, this concept has been described in the literature and the information can be used to guide the teaching of patients receiving oral chemotherapy.

Clinicians generally assume that patients are taking medications as prescribed and believe their patients when they say they are doing so (Partridge, Avorn, Wang, & Winer, 2002). In chronic medical conditions, such as diabetes and hypertension, estimates of medication nonadherence range from 15%–93% (Myers & Midence, 1998). Although patients with cancer are thought to be highly motivated by the gravity of their disease (Waterhouse, Calzone, Mele, & Brenner, 1993), a noncompliance rate of 43% was reported in a study of 51 outpatients with breast cancer who received 26 weeks of oral cyclophosphamide (Lebovits et al., 1990).

A study examining allopurinol and prednisone compliance in a cohort of outpatients who received concomitant chemotherapy for hematologic malignances found that, with no interventions, complete compliance with the oral medication regimen occurred in only 17% of the patients (Levine et al., 1987). Furthermore, pharmacokinetic analysis found that actual compliance was less than half that suggested by patients’ self-reports. However, the researchers also found that measures designed to increase compliance, including patient education, home psychological support, and exercises in pill taking, were able to increase compliance nearly threefold (Levine et al.).

Measuring compliance is challenging at best. Pill counts can be unreliable because patients can manipulate them, especially when they know their pills will be counted. Also, pill counts do not confirm adherence to a particular dosing schedule. The microelectronic monitoring system (MEMS) is a newer method to assess compliance. The system uses an “intelligent” tablet bottle that electronically records the date and time (to the nearest hour) when the cap is removed. Data are collected for up to several weeks, recorded, and processed by a computer to generate a list of the dates and times of bottle openings and a graph of the number of doses taken daily, the number of missed or extra doses, and the dosing intervals (Partridge et al., 2002). Although opening of a pill container does not necessarily mean that the patient ingested the pill as prescribed, MEMS may help to provide a more accurate assessment of a patient’s medication compliance.

Noncompliance affects all age groups, but older patients are more vulnerable to...
compliance problems because of age-related barriers, such as visual and cognitive impairment, memory deficits, physical limitations, unpleasant side effects, and lack of social support (McGraw & Drennan, 2001; Ryan, 1999). Among patients 60 years and older, medication noncompliance is reported to range from 26%–59% (van Eijken, Tsang, Wensing, de Smet, & Grol, 2003). Considering that cancer tends to be a disease of the elderly, this has important implications for oncology nurses.

Much remains to be learned about the relationship between psychosocial characteristics and medication adherence, especially in the oncology population. However, several factors appear to be important (Partridge et al., 2002).

- Ability to follow the prescribed regimen, which is related to the complexity of the regimen, including dosage frequency
- Ability to adhere to the regimen, which is related to the degree of behavioral change required and duration of therapy
- Convenience and efficiency of the healthcare setting
- Adequacy of healthcare provider supervision and communication
- Patient satisfaction
- Patient health beliefs, including a patient’s degree of belief that the regimen will help or is worth the risks or costs
- Adherence history
- Mental illness history
- Family stability and sufficiency of social support

Oncology nurses need to consider these factors and assess patients for risk of noncompliance, such as missed clinic visits for unexplained reasons or a history of self-modulating doses of other medications (Sharma, 2001). The results of the assessment will shape the individual patient’s teaching plan and follow-up care.

Patient Education

The role of the oncology nurse in patient education has been well established for many years. The literature is rich with information on patient teaching, and numerous resources abound. A review of randomized controlled trials to assess a variety of methods for providing information about cancer treatment suggests that teaching methods should be based on patient preferences and individually tailored rather than uniformly administered (McPherson, Higginson, & Hearn, 2001). The following section focuses specifically on patient education as it relates to oral chemotherapy agents and is presented in the context of who, when, where, and what.

Who and When?

When administering IV chemotherapy, oncology nurses are in a prime position to provide patient teaching because the patient and family members are a “captive audience” in the infusion area. This is not the case for patients receiving oral chemotherapy agents as their only cancer treatment. In small clinics and office-based oncology practices, nurses primarily are stationed in the infusion rooms. Patients taking oral chemotherapy may receive their prescriptions and medication information directly from their oncologist or pharmacist and never see an oncology nurse. These patients may not see an oncology nurse during follow-up visits either. The oncology nurse’s usual chemotherapy-education visit or patient-teaching session provided to patients starting IV chemotherapy is not scheduled nor performed. Just like patients receiving IV chemotherapy, patients receiving oral chemotherapy need to receive patient education from an oncology nurse. A review of medication compliance studies published from 1990–1998 found that education and reminders are especially important at the beginning of treatment (Wood & Gray, 2000).

Although the oncology nurse often is the primary educator of patients and family members, the oncologist and pharmacist also are very important in the educational process. As in many other patient care situations, the oncology nurse acts as a liaison with the patient taking oral chemotherapy and his or her primary caregiver, oncologist, and community pharmacist. Developing a rapport and helping patients and caregivers feel comfortable enough to ask questions are key goals of the teaching process. For example, building trust encourages patients to be honest about missed or late doses of their oral chemotherapy. Dosage adjustments based on side effects associated with patients’ reported doses can negatively affect clinical outcomes if patients are not reporting honestly.

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Another important consideration in the “who” of patient education is including the caregivers at home who may or may not be family members. Other people may have a major influence on patients taking medications as prescribed, and, in some cases, those other people may be administering the oral chemotherapy and assessing for side effects. Even in situations in which a patient is fully capable of self-dosing and self-assessment, the complexity of chemotherapy is considerable and educating additional home caregivers is beneficial.

Where?

Patient education is an ongoing process that occurs in the clinic or oncology office, at the patient’s pharmacy, and over the telephone. In the clinic or office setting, a quiet room without distractions or interruptions will help the educational process tremendously. However, staffing shortages in today’s healthcare environment can threaten the success of the patient-teaching process. Patients are less apt to ask questions and raise concerns if nurses appear stressed, tired, or too busy. Scheduling chemotherapy teaching sessions late in the afternoon should be considered because most patients receiving IV chemotherapy prefer morning appointments and the late afternoon time is generally less hectic.

Telephone follow-up and triage of patients receiving oral chemotherapy often are focused on symptom management. During telephone calls, information is reinforced as well as obtained. Many patients already take multiple oral medications and may become overwhelmed with yet another medication. For these patients, extra precautions and support are needed, such as making frequent follow-up phone calls, prescribing only one cycle of oral chemotherapy at a time, and offering organizational or pharmaceutical support programs. Medication compliance aids (e.g., diaries, calendars, pillboxes with built-in timer alarms, multialarm wrist watches, pagers with alarm and text reminders) also may be helpful to patients on oral chemotherapy regimens.

What?

Thorough verbal and written instructions about oral chemotherapy should be provided and include the following.

- **Name of the medication** (both generic and brand, when appropriate): Instruct the patient to compare carefully the prescription bottle and pharmacy directions with the written instructions provided by the clinic.

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or oncology office staff. Poor handwriting, use of abbreviations, and other factors can lead to medication errors. Patients and their family members need to take an active role in double checking medications and preventing medication errors.

- **Dose and schedule:** If the patient’s prescribed dose requires taking different dose-sized tablets or capsules, the use of a pillbox organizer may be helpful. Providing a calendar with the patient’s oral chemotherapy schedule can help to ensure accuracy in adhering to the correct dose and schedule as well as serve as a reminder for follow-up laboratory tests and clinic or office visits (see Figure 1). Telephone-linked reminder systems also may be helpful (e.g., automated reminder systems) (Krishna, Balas, Boren, & Maglaveras, 2002).

- **How the medication is taken:** Patients must be informed of special instructions (e.g., taking the medication with food, food-drug interactions to be avoided), the importance of not doubling up to make up for a missed dose, and the absolute importance of “truth-telling” when reporting the degree of accuracy in taking the chemotherapy as prescribed. Patients must understand that dose adjustments are based on reported side effects and that inaccurate information may result in harm. Patients need understanding and reassurance when they admit to mistakes or lapses in following oral chemotherapy instructions. Further assistance and safety mechanisms should be put in place to help with adherence. Nurses may need to consult the prescribing oncologist to discuss the appropriateness of oral chemotherapy for patients who continue to have problems with adherence.

- **Safety:** Patients must be instructed in the proper storage of chemotherapy to maintain the medication’s efficacy and to prevent accidental ingestion (e.g., keep out of reach of children or pets). Patients should be instructed not to crush tablets or open capsules (this is not advisable because of the biohazardous nature of these products). After ingestion of chemotherapy, emesis, urine, and stool should be treated as biohazardous substances and the entire household should be aware of the risks of exposure and how to handle patients’ bodily fluids (Birner, 2003). Patients and families need to be instructed in the importance of follow-up laboratory tests, follow-up appointments, or other assessments required before patients can obtain clearance to begin another cycle of oral chemotherapy. In the beginning, prescribing only one course of oral chemotherapy at a time and not refilling prescriptions over the phone will lessen potential confusion and promote adherence with the treatment plan.

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**Figure 1. Example of a Calendar That Can Be Given to Patients Receiving Oral Chemotherapy**

<table>
<thead>
<tr>
<th>SUNDAY</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
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<tbody>
<tr>
<td>17</td>
<td>18</td>
<td>19</td>
<td>20</td>
<td>21</td>
<td>22</td>
<td>23</td>
</tr>
<tr>
<td>10:30 am—Dr. visit, lab work</td>
<td></td>
<td>Start Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
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<table>
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<tr>
<th>24</th>
<th>25</th>
<th>26</th>
<th>27</th>
<th>28</th>
<th>29</th>
<th>30</th>
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<tbody>
<tr>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
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<th>31</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Xeloda</td>
<td>Labor Day—office closed</td>
<td>11 am—complete blood count, nurse practitioner visit</td>
<td></td>
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<th>10</th>
<th>11</th>
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</thead>
<tbody>
<tr>
<td>Dr. visit, lab work</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
<td>Xeloda</td>
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<td>Xeloda</td>
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Things to do: Reminder: Take with food.

Note. Xeloda® (Roche Pharmaceuticals, Nutley, NJ)
Side effects and symptom management: Patients and families must be instructed about potential side effects, self-help measures to manage these side effects, and when and how to contact the clinic or oncology office. Patients often have a lack of appreciation for the potential seriousness of not reporting toxicities that develop (Hollywood & Semple, 2001). Oncology nurses need to help patients understand that early recognition of and prompt intervention for potentially serious side effects (even if a chemotherapy dose reduction is required), in the long run, can be of far greater benefit to them than ignoring side effects or being hesitant to report them.

With IV chemotherapy, the oncologist has far greater control over dosing and dose adjustments. With oral chemotherapy, patients—to some degree—are responsible for making dose adjustments in their own therapy, as determined by their willingness and ability to report side effects early (Hollywood & Semple).

Pharmaceutical manufacturers provide excellent patient education materials. Their booklets on specific medications and Web sites are helpful resources for take-home information and reinforcing instructions for patients.

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References


For more information on this topic, visit the following Web sites.

James Hospital Patient Education Packages
www.acs.ohio-state.edu/units/osuhosp/patedu/Materials/PackageIndex-james.htm

University of Pittsburgh: Patient Education Materials
http://patienteducation.upmc.com

TransMed: Patient Education Chemotherapy
www.breastdiseases.com/pe10.htm

Links can be found at www.ons.org.

Rapid Recap

Patient Education: The Cornerstone of Successful Oral Chemotherapy Treatment

- Adherence to oral medication regimens, including oral chemotherapy, is influenced by the ability and desire of patients to adhere to a regimen, adequacy of supervision by healthcare providers, patient health beliefs, adherence and mental health history, family stability, and social support.
- Teaching methods should be based on patient preferences and individually tailored.
- Oncology nurses, along with oncologists and pharmacists, are the primary educators of patients receiving oral chemotherapy.
- Education of patients receiving oral chemotherapy is an ongoing process that occurs in the clinic or office, at the pharmacy, and over the telephone.
- Minimally, patients receiving oral chemotherapy need to be taught about the medication, dose, and schedule; how it is taken; safety precautions (e.g., the biohazardous nature of these agents); and side effects and symptom management.
- Pharmaceutical manufacturers and organizational Web sites offer written information and educational resources to supplement verbal instruction.