The Patient: Our Teacher and Friend1

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Pharmacy educators challenge and teach pharmacy students and practitioners to change and expand their practice roles in the pursuit of the provision of pharmaceutical care. Yet, there is a dearth of research and information about the provision of pharmaceutical care from the patient’s perspective. Using an introspective research method we present an actual case study of a patient who suffered an episodic illness that required drug therapy treatment and the provision of pharmaceutical care. From the patient’s perspective we: (i) describe the illness episode and treatment regimen; (ii) describe and discuss solutions to patient care situations such as patient involvement in diagnosis of illness, treatment of pain after surgery, patient involvement with drug therapy risk assessment, patient therapeutic outcomes monitoring and risk management, disease and drug information overload, the role of the patient advocate, and patient coping, adaptation and control associated with illness and treatment; and (iii) briefly discuss literature that is related to the patient’s actions and behaviors. From the patient’s experiences we pose a number of issues for pharmacy educators to address in the design of professional curricula to include experiential clerkships.

INTRODUCTION

As educators and health care professionals, the primary reason for our existence is patients. They are the consumers, customers or clients of our services. Without patients there would be no need for dental, medical, nursing or pharmaceutical care. Pharmacy educators challenge and teach pharmacy students and pharmacists to change and expand their practice roles in the pursuit of pharmaceutical care, that is, “the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve the patients quality of life (1).” Thus, patients supposedly are the foundation upon which pharmacy education is built.

What do pharmacy educators and practitioners know about a patient’s needs, expectations and desires as they relate to the provision of pharmaceutical care? In a review of the pharmacy literature there is a paucity of either quantifiable descriptive or empirical case studies about a patient’s perspectives and thoughts related to the provision of pharmaceutical care. Therefore, to gain an insight and learn more about a patient’s perspective in the practice of pharmaceutical care we present an actual case study of a patient who suffered an episodic illness that required drug therapy treatment and the provision of pharmaceutical care.

Our patient is named George and his wife’s name is Martha. They used an introspection method of research to tell their story (2). We divide their story into three Sections. In Section I we describe George’s illness episode and treatment regimen which includes Martha’s involvement. In Section II, we describe and discuss problems that George and Martha encountered in the diagnosis and treatment of the illness. The problems are related specifically to the delivery of pharmaceutical care. We describe each problem, present George’s and Martha’s solutions and describe research that relates to their decisions and behaviors. Then, in Section 3 we list a number of issues that educators and practitioners could address when they design curricula and experiential clerkships for pharmacy students and practitioners.

SECTION I: GEORGE’S ILLNESS EPISODE AND TREATMENT PROTOCOL

George was a 45-year-old teacher with no previous history of medical problems. He never had been hospitalized for an illness. He rated his health as excellent. In the early morning hours of his 45th birthday George noticed a large amount of bright red blood in his watery stool. What caused this, he wondered? Maybe one of his hemorrhoids ruptured? Or maybe the super, spicy chili he ate the evening before had caused the problem.

He was alarmed and concerned. He had a mental flashback. His father-in-law died of colon cancer; he too had a sudden occurrence of blood in his stool. George thought, surely, this cannot be a replication of what happened to his father-in-law. George did not flush the stool. Instead he woke his wife Martha and told her about the blood. He asked “could you look at the stool?” Martha, a critical care nurse for 27 years, examined the stool and became alarmed. The stool had bright red blood in it, a very large quantity too. She questioned George extensively about how he felt. Light headed? Dizzy? Nauseated? She continued asking questions to which George responded, “I feel just fine. And I do not have cancer like your dad did.” Yet, the question still gnawed at them, why did George have so much bright red blood in his stool? Did he have a bleeding ulcer? Or was it something else he did not want to even imagine?

The next morning Martha arranged for George to see a gastroenterologist. A sigmoidoscopy was performed and many lab tests conducted. Neither the sigmoidoscopy nor the lab test results were abnormal. The gastroenterologist conferred with other physicians. None of them could explain why George had blood in his stool, yet the occult blood test was still positive.

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1 Portions of this article were presented at the 96th Annual Meeting of the American Association of Colleges of Pharmacy Social and Administrative Sciences Section Program titled “Pharmaceutical Care: The Lost Patient,” Philadelphia PA, July 9, 1995.
George’s concerns grew. He sensed that something was wrong. Things just did not make sense. Again, he had a flash back to his father-in-law’s illness and death. George asked his physicians to perform a colonoscopy. They agreed and further suggested an endoscopy too because they could not determine the source of bleeding. Both procedures were performed the next day.

The endoscopy showed that George suffered from gastric reflux and ranitidine was prescribed for treatment. The colonoscopy results showed a three centimeter tumor located in the ascending colon about ten centimeters from the cecum. No other tumors were found. On the 28th day after George first discovered blood in his stool he received the pathologist’s report from his gastroenterologist. George had adenocarcinoma of the large intestine. George had colon cancer just like his father-in-law. The gastroenterologist suggested only one treatment—immediate surgery! George and Martha met with the surgeon the same afternoon they had learned about the cancer. The surgeon wanted to operate the next day but George and Martha postponed the surgery for a day so they could notify family, friends, and fellow workers about his condition.

The surgeon removed the tumor, resecting the ascending colon and portions of the transverse colon, and performed an end to end anastomosis. The pathologist identified the tumor as moderately differentiated and labeled it a Duke’s stage B2 tumor (3), that is, the tumor perforated the wall of the colon but there was no lymph node involvement. George remained in the hospital for five days to ensure initial recovery from surgery, adequate pain management, bowel function and nutrition.

A day after discharge from the hospital George complained about abdominal pain and cramps. They were so severe that George thought he had an obstructed bowel. Should he take more stool softeners or maybe even a laxative? The pain increased to the point he could neither sleep nor rest comfortably. Martha called the surgeon and explained George’s condition and symptoms which were diagnosed as postoperative colitis. The occurrence of colitis probably was due to a combination of causes such as the cleansing of the bowel, high doses of antibiotics prior to surgery and the surgery itself. The surgeon prescribed azulfidine; the treatment was successful.

The surgeon and gastroenterologist referred George and Martha to an oncologist to determine if George needed either radiation or chemotherapy. The surgeon suggested to Martha that when selecting an oncologist they make sure to find someone who not only is competent in the field but also someone who works well with patients and has a positive attitude. Martha contacted a friend who worked in an oncology clinic. Martha described George’s situation to her friend and asked for a recommendation.

Using the information they learned from Martha’s friend, George and Martha selected an oncologist. They met with the oncologist to discuss therapy options, one of which was 5-FU and leucovorin. At the end of the meeting, which lasted for two hours, George and Martha decided to select the adjuvant chemotherapy regimen of 5-FU and levamisole. Their oncologist told George and Martha their journey for the next year would be difficult. He informed them that George was the boss and that he, the oncologist, worked for George.

The initial chemotherapy regimen was a five day loading dose of 5-FU which lasted for one month and a biweekly regimen of levamisole, three times a day. It was given every two weeks over three days with one tablet given three times a day. After the one month loading dose of 5-FU George received a weekly dose of 5-FU and the biweekly regimen of levamisole for 12 months. To control nausea George received ondansetron 8 mgm three times a day as needed on days of therapy. On Halloween, 14 months after George found blood in his stool, he completed his chemotherapy protocol. Table I contains a chronological listing of George’s illness episode and treatment.

**SECTION II: PATIENT CARE SITUATIONS ENCOUNTERED BY GEORGE**

Here we address some of the patient care problems George and Martha encountered in the diagnosis and treatment of his illness, especially the delivery of pharmaceutical care. The list is not all inclusive of George’s and Martha’s experiences. In Section 1 we presented George’s illness and treatment episode in a medical case format. Now, in this Section we retrace some of those situations and elaborate upon them from George’s perspective as to his care prob

<table>
<thead>
<tr>
<th>Month and day</th>
<th>Event / episode</th>
</tr>
</thead>
<tbody>
<tr>
<td>September 1994</td>
<td>Detected blood in his stool while moving his daughter to college.</td>
</tr>
<tr>
<td>5</td>
<td>Flexible sigmoidoscopy and lab tests performed, reported normal.</td>
</tr>
<tr>
<td>16</td>
<td>Met with gastroenterologist; scheduled endoscopy and colonoscopy.</td>
</tr>
<tr>
<td>30</td>
<td>Colonoscopy and endoscopy performed; discovered a 3cm tumor in George’s ascending colon.</td>
</tr>
<tr>
<td>October 1994</td>
<td>Met with gastroenterologist; told tumor was cancerous; met with surgeon to discuss tumor removal.</td>
</tr>
<tr>
<td>3</td>
<td>Removed tumor, bowel resected, and performed end to end anastomosis.</td>
</tr>
<tr>
<td>5</td>
<td>Dismissed from hospital.</td>
</tr>
<tr>
<td>12</td>
<td>Suffered postoperative colitis at home.</td>
</tr>
<tr>
<td>18</td>
<td>Met with oncologist; tumor classified as Duke’s stage B2; discussed radiation and chemotherapy treatments; decided chemotherapy protocol with 5-fluorouracil and levamisole.</td>
</tr>
<tr>
<td>31</td>
<td>Began chemotherapy, loading dose of 5-fluorouracil for five days, plus a 3 day bi-weekly regimen of levamisole -1 tablet three times a day.</td>
</tr>
<tr>
<td>November 1994</td>
<td>Received 3 day regimen of levamisole -1 tablet three times a day.</td>
</tr>
<tr>
<td>14</td>
<td>Began combination treatment regimen, 5-fluorouracil weekly injections and levamisole 1 tablet three times a day for 3 days every other week.</td>
</tr>
<tr>
<td>28</td>
<td>Completed the one year chemotherapy protocol.</td>
</tr>
</tbody>
</table>
lems and needs. The situations include: patient involvement in diagnosis of illness, treatment of pain after surgery, patient involvement with drug therapy risk assessment, patient therapeutic outcome monitoring and drug therapy risk management, disease and drug information overload, the role of patient advocate, and patient coping, adapting and controlling experiences.

Patient’s Involvement with Diagnosis of Illness

George had a dilemma. All lab tests and sigmoidoscopy results were normal, although results from an occult blood stool test showed he still had blood in his stool. George’s problem was not knowing what caused the blood in his stool? George knew about another diagnostic procedure, a colonoscopy, because it had been performed on Martha and her father. He also knew he had health insurance that enabled Martha and he to be active participants in choosing their health care providers. For example, their insurance coverage allowed self-referrals to specialists rather than seeking a referral through a primary care physician performing a gate keeper role.

In determining whether or not to have the colonoscopy George evaluated the risks and benefits of the procedure. He knew insurance would cover the procedure if he could convince the physician to order it. He pondered what the benefits are of a colonoscopy? Maybe it will help determine the cause of the bleeding? What are the consequences or risks if I do not have a colonoscopy? Maybe it forgoes the discovery of the cause of the bleeding? Can I afford to wait longer? George remembered his father-in-law’s situation and Martha’s fears. His cancer was discovered at the first sign of blood and it was still too late. George knew he needed the colonoscopy and knew he had to request it. His physician team listened to his request and agreed to it. They too were puzzled with the bleeding and they recommended the colonoscopy along with an endoscopy.

Thus, George and his team of physicians worked together to identify his medical problem. Physicians recognized the need to practice patient-centered medicine (4). They listened to George, learned from his life experiences and recognized him as an active participant in choosing his care.

Treatment of Pain after Surgery

When George returned from surgery the anesthesiology resident told George he wanted to ensure George’s pain was under control. The resident told George it was his job to make him feel comfortable and not be in pain. At the foot of George’s bed, on the wall was a chart which read “pain management scale.” The scale was numbered one through ten with numbers 1 and 2 labeled ‘Low’, numbers 3,4,5 labeled ‘Mild’, numbers 6,7,8 labeled ‘Moderate’ and numbers 9 and 10 labeled ‘Severe’. George was instructed to pick a number on the scale that reflected his level of pain. Nurses and physicians would use that information to determine the amount of pain medication George would receive.

Table II. contains the three stages of pain management that George received. For each stage the name of the drug, strength, route of administration and dosage schedule is listed. While on the morphine continuous infusion and the intravenous meperidine, George rated his pain level between 2 and 4 on the pain management scale. He slept well.

On the third day in the hospital, George’s intravenous therapy was discontinued. His pain medication was switched from meperidine to the oral drug acetaminophen/oxycodone. His last dose of meperidine was 2200 hours, just after Martha left for home. At 0100 hours the next morning George awoke, he was in pain. He rated his pain as a 5 on the scale. He pressed the call button to alert the night nurse. The nurse came and George requested additional pain medication. George remembered the anesthesiology physician’s daily comment, “George, we want to make you feel comfortable and not be in pain.” The attending nurse told George he’d have to wait another hour before he could give him any more pain medication. It had not been four hours since George received his last dose of meperidine. The acetaminophen/oxycodone combination wasn’t to be given until 0200 hours. George pleaded with the nurse but to no avail, and the nurse left. In the next 30 minutes George’s pain worsened, he now rated it as a 7 on the scale. He could not sleep and sweated profusely. Again, George pushed the call button to summon the nurse.

The nurse came and again told George “You cannot have any pain medication until 0200 hours. That’s as soon as I can give you the medication.” The nurse left and returned at 0300 hours and gave George a tablet of acetaminophen/oxycodone, an hour after the 0200 hours scheduled time of the dose. George was awake, irritable and rated his pain between 6 to 8 on the scale. When Martha arrived in George’s room at 0600 hours she found George very fatigued. She could tell from the expression on his face he was still in pain. George told her about the incident with the night nurse, how he had argued and pleaded with the nurse to receive pain medication but to no avail. Martha left the room immediately and returned shortly with another nurse and additional pain medication for George.

George’s control of pain could have been rectified immediately if physicians, nurses or pharmacists had recognized a drug bio-availability problem. When George was moved from the intravenous injection of meperidine to the oral medication, acetaminophen/oxycodone, the dosing interval remained every 4 to 6 hours, no one adjusted the dosage interval to account for slower onset of action for the orally delivered pain medication versus parenterally delivered route. A simple solution would have been to start the oral medication sooner before the four hour increment of intravenous meperidine had been completed. George’s pain level initially was low to mild yet it increased to the upper moderate level because of a drug scheduling problem. It was complicated further when the nurse refused to respond to George’s increased pain needs and was an hour late in giving the oral pain medication. No physician, pharmacist or nurse either recognized or solved George’s drug bio-availability problem to George’s satisfaction.

Table II. Pharmaceutical care problem: Post-surgical pain management therapy

<table>
<thead>
<tr>
<th>Stage</th>
<th>Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Continuous infusion of morphine</td>
</tr>
<tr>
<td>Two</td>
<td>Morphine discontinued, replaced with meperidine intravenously every four to six hours.</td>
</tr>
<tr>
<td>Third</td>
<td>Intravenous solution discontinued, meperidine discontinued; acetaminophen/oxycodone by mouth every four to six hours as needed for pain.</td>
</tr>
</tbody>
</table>

Patient Involvement with Drug Therapy Risk Assessment

Prior to meeting with the oncologist, George began
reading about colon cancer and treatments. The primary
drug information source George used were drug package
inserts given to him by the oncology clinic pharmacist.
George and Martha had to make a difficult decision, that is,
whether or not to seek adjuvant chemotherapy. George’s
tumor was staged as a Dukes’s stage B2. Reports from clinical
trials research which were later published (5) showed that a
survival benefit from adjuvant chemotherapy had not been
demonstrated in patients classified with Duke’s stage B2,
however, patients with Duke’s stages B3 and C had received a
survival benefit with adjuvant therapy. Researchers postu-
lated that the lack of a survival benefit for patients classified
as Dukes stage B2 probably was due to a low sample size in
the clinical trials. Clinical researchers believed there would
be a survival benefit associated with adjuvant chemotherapy
for patients classified as Duke’s stage B2 once more patients
were enrolled in clinical studies. Martha strongly believed in
the relationship between the cancer and the body’s immune
system. A perceived benefit from adjuvant chemotherapy
would be a stimulation of the body’s immune system to
attack any remaining cancer cells in George’s body. They
systematically evaluated the risks and benefits of the adju-
vant chemotherapy. In their evaluation they thought and
discussed therapy’s impact on their lifestyles, marriage,
children, work and the treatment effects on George’s life
-psychologically and physiologically. They decided to pro-
ced with adjuvant chemotherapy because they believed it
increased George’s chances of survival from the deadly
disease.

Now George and Martha had to choose between two
drug regimens, 5-FU and levamisole or 5-FU and leucovorin.
George and Martha discussed with their oncologist many
issues about therapy such as benefits, major side effects,
protocol duration, patient tolerance, alternative therapies
and the impact of each therapy regimen on family, life style,
and work. George’s oncologist insisted they work together
as partners in this therapy addressing their needs and wants
and how they could be coordinated with the therapy proto-
col. George’s oncologist reminded George, “I work for you.
You are the boss. I’ll answer your questions to the best of
my ability but in the end you are the one who calls the shots.”
At the end of this clinic visit, George and Martha chose the 5-
FU and levamisole regimen because the side effect profile
was less severe with levamisole compared to leucovorn, and
levamisole offered a better immunological benefit.

While preparing himself for chemotherapy, George
reviewed the side effect information provided by his
oncologist. Since one of the side effects of the therapy was
nausea, George wanted to ensure he had the best medica-
tion for that purpose. Again, he spoke to the oncology clinic
pharmacist. George knew him because he had helped in the
treatment of George’s father-in-law’s colon cancer. George
asked the oncology pharmacist his opinion on what was the
best drug for treating nausea associated with a 5-FU and
levamisole regimen. This was important to George because
he remembered the terrible symptoms his father-in-law
experienced and feared during chemotherapy. The oncology
pharmacist replied, “If your insurance covers it, go with
ondanetron. It’s expensive but it’s much better than the
prochlorperazine we gave your father-in-law, fewer side
effects, works better.” He also gave George a drug product
package insert for both drugs. After reviewing the informa-
tion and discussing it with the oncology pharmacist, George
contacted his oncologist and they decided to use ondanetron
8mgm three times a day as needed to control his nausea.

George arrived for his first day of therapy on October
31st - Halloween. He was seated in the oncology treatment
room. A clinic nurse told George he would receive a shot of
5-FU, one tablet of levamisole and a tablet of prochlorperazine
10mgm to control the nausea. George told the
nurse there was some mistake, he was to receive ondanetron
8mgm three times a day as needed for nausea. His
oncologist had written an order for that. She replied,
“No way! All patients on this protocol receive prochlorperazine.
Besides your oncologist did not write a prescription order for ondanetron.
So just take this medica-
tion for your nausea.” George refused to take the
prochlorperazine and requested his oncologist be contacted.
Martha was there and supported George. The nurse again
refused to contact George’s oncologist.

Then George saw the oncology pharmacist appear in the
oncology pharmacy dispensing window in the clinic treat-
ment room. George explained the situation to him. The
oncology pharmacist intervened and asked the nurse to
contact George’s oncologist for the prescription order. She
obliged and received the okay to write the prescription
order. As an agent of the prescriber she wrote a prescription
order for ondanetron 8mgm twice a day instead of three
times a day as needed. George told her it wasn’t correct but
instead of arguing anymore he completed his infusion of the
5-FU, took the levamisole tablet and left the clinic extremely
frustrated and tired. He was mentally fatigued and asking
himself why should I become involved? The nurse badgered
him and treated him like he must follow her orders. Martha
felt helpless as she tried to intervene but to no avail. As they
left the clinic George began to experience the side effects of
the chemotherapy, in particular the nausea.

George immediately went to his family pharmacist to
have the ondanetron prescription filled and dispensed. He
informed his pharmacist that the directions should be three
times a day as needed rather than two times a day. His
pharmacist concurred and called the clinic to contact the
physician. Instead, the clinic nurse intervened and argued
with George’s pharmacist about the dosing directions. The
directions were not changed. George’s pharmacist labeled
the prescription accordingly but told George to take it three
times a day as needed instead of the two times a day as
printed on the label.

In the selection of chemotherapeutic drugs and the
drugs to treat side effects the oncologist and oncology
pharmacist, used the collaborative Client-Centered Model
approach to delivery of pharmaceutical care (6). Drug choice
decisions were based upon the use of drug therapy risk
assessment information as described by Brushwood (7).
Each clinician, except one oncology clinic nurse, recognized
George as an active partner working with his physicians,
pharmacists and nurses to define his therapy options. Yet,
the oncology clinic nurse did not use the Client-Centered
Model approach which requires system coordination to
make client/patient centered models work (6). Instead, she
used the Medical Model approach for medication decision
making and management (6). Interestingly, even though
George’s advocate Martha, was also a nurse, she was not
considered a partner in that health care decision. The nurse
assumed the patient to be a passive partner in determining
drug product selection. The nurse told the patient what to
do, expected the patient to do it and not to question the
nurse’s authority. The nurse thought that she was in charge.
Table III. Examples of side effect information contained in the drug therapy monographs for 5-fluorouracil and levamisole

5-Fluorouracil

Common Side Effects:
Loss of Appetite, Diarrhea, Blahs, Mouth Sores, Splitting of Fingernails, Dry Flaky Skin, Metal Taste in Mouth, Darkening of Skin especially on face and palms of hands, Watery Eyes, Nasal Congestion.

Reduced Blood Counts May Occur 10-14 Days After Treatment

Less Common Side Effects:
Nausea and Vomiting, Thinning of Hair, Skin Rash, Abdominal Cramps, Difficulty with Coordination.

Special Precautions:
Your Skin is Sensitive to the Sun, Use a Sun Screen

Levamisole

Common Side Effects:
Mild Nausea and Vomiting, Change in Sensation of Taste, and Smell, Decrease Appetite in High Doses, Drowsiness, Lethargy, Flu-Like Syndrome with Prolong Use

Less Common Side Effects:
Skin Rash and Itching, Insomnia, Nervousness, Irritability, Reduced Blood Counts

Patient Therapeutic Outcomes Monitoring—Drug Therapy Risk Management

When George began his chemotherapy treatment the physicians and nurses gave him drug information leaflets that described the drug, how it was given, common side effects, less common side effects, special precautions and storage conditions. Table III. contains examples of some of that information. The nurses and physicians told George and Martha to monitor the side effects especially loss of appetite, diarrhea, nausea, and mouth sores. If these side effects occurred and they were serious enough George and Martha were told that medications could be prescribed to treat some of them. They also told George that they would monitor his blood chemistry and hematology values, especially white and red blood cell counts for erythropenia and leukopenia.

No one instructed George how to monitor side effects and how to document their frequency, variability and severity of occurrence. George decided on his own what to do. He designed a one page form to monitor and record side effect experiences, and measure their frequency of occurrence, variability and subjectively rate their severity. He titled the form Neptune Patient Side Effect/Medication Profile Log. We present the form in Tables IV and V.

On the back side of the form (See Table IV.) George listed his medications. He developed a key to describe the measures of frequency of occurrence, variability and severity. Side effects which were best measured by frequency of occurrence were recorded as a number and circled on the form. Daily variability of a side effect was measured as a dichotomous variable ‘C’ to represent constant occurrence and ‘V’ to represent variable occurrence during the day. To measure the level of severity of a side effect George adapted the summative 10-point pain management scale that he used when hospitalized. Scale values and labels were similar to the pain management scale. Under the list of medications George wrote comments about his medication self-administration behaviors.

On the front page of the Neptune Patient Side Effect/Medication Profile Log (see Table V.) there is a space to list side effects that George described in non medical terms, space to record side effect measures, and space for comments. George recorded the date and types of medications taken daily. For example, on October 31st George took six medications, recorded as numbers 1 - 6. The number corresponds to the medication number recorded in the medication profile (See Table IV.). George used the information from the drug information leaflets (See Table III.) to document 10 side effects he experienced during his first 17 days of therapy.

Table V. contains the data from the first treatment period October 31st, the actual day treatment started, through November 16th. During this period George received the initial five day loading dose of 5-FU from October 31st - November 4th and two bi-weekly, three day regimens of levamisole. October 31st - November 2nd and November 14th - 16th. He used ondansetron October 31st - November 4th. He took the remaining three medications, those numbered 4-6, concurrently for the entire period.

George recorded the side effect “itching” occurring from November 1st -11th. It varied daily, and severity rating ranged from 2 initially to a rating of 4 on the November 6th to 7 occurrence on the 12th. Itching had a footnote ‘c’ which George described in the comment section as itching occurring under the arms and rectum. Notice that the side effect “diarrhea” occurred on November 2nd through November 11th ranging from two to five times a day to “no occurrence” on November 14th.

George described the side effect “smell changed” as putrid and noted that it occurred most often when running water from a facet, showering, when it rained or when it was a humid day. Sometimes when George experienced this side effect he became nauseated. George told us that the first time he took a shower after being on the medication the water smelled like it came from the sewer. For the side effect “smell changed” George rated it from a level of ‘2C’ on November 1st to a rating of ‘6C’ from November 3rd through

Table IV: Neptune patient side effect/medication profile log backside of form: Data from George's therapy

<table>
<thead>
<tr>
<th>Medication profile (Prescription and OTC drugs)</th>
<th>Measures key</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 5-Fluorouracil - 950 mgm Injection Weekly</td>
<td>a. Frequency</td>
</tr>
<tr>
<td>2. Levamisole 50 mgm, three times a day every other week</td>
<td>b. Daily Variability</td>
</tr>
<tr>
<td>3. Ondansetron 8mgm, one tablet three times a day as needed</td>
<td>c. Severity Rating</td>
</tr>
<tr>
<td>4. Ranitidine 150mgm, one tablet twice a day.</td>
<td>Scale</td>
</tr>
<tr>
<td>5. Vitamin C, one gram every day.</td>
<td>1, 2 = Low</td>
</tr>
<tr>
<td>6. Multivitamin</td>
<td>3, 4, 5 = Mild</td>
</tr>
<tr>
<td></td>
<td>6, 7, 8 = Moderate</td>
</tr>
<tr>
<td></td>
<td>9, 10 = Severe</td>
</tr>
</tbody>
</table>

Comments on Medication Taking Behavior

5 - Fluorouracil when injected feels cold

Levamisole - tablets are bitter tasting
6th to “no reported occurrence” on November 11th. The side effect “smell changed” occurred again on November 14th at the same time George began his three day therapy of levamisole. Thus, the second to fourth week of his treatment protocol in which he did not receive 5-FU George learned more about side effects associated with levamisole.

George received many benefits from the side effect monitoring system. Initially, when he had monthly follow-up appointments with his oncologist, the nurse just asked him if he experienced the side effects of loss of appetite, nausea, mouth sores or diarrhea; and inquired about their frequency and degree of severity. Not only was George able to report the side effects that were important to the clinicians, he also reported the other side effects he experienced including their frequency, variability, and a subjective rating of their degree of severity. He prepared for his follow-up clinic visits by summarizing and prioritizing the side effect data that he believed were important to share and discuss with the clinicians. George and his oncologist thought such preparation made more effective and efficient use of their time at the clinic visit. Clinicians entered the side effect information into George’s medical record and used the data to address George’s requests and treatment needs. For example, sometimes based on severity of the nausea the clinician and George adjusted the dosing of ondansetron. As therapy progressed the clinicians expected George to tell them how he felt and what side effects were giving him problems so they could work in collaboration with George to resolve problems. The clinicians considered George an active and responsible partner in his care.

He observed that clinicians had their desired set of side effects they wanted to monitor which probably was due to their degree of clinical significance. For George, all side effects were important. George understood why the clinicians needed to monitor specific side effects, yet he noted his overall quality of life was affected by simple side effects such as the itching rectum or the putrid smell caused by the running of tap water or when it rained.

Essentially, George taught himself how to monitor his side effects and learned what to expect as his therapy progressed. George completed the Neptune Patient Side Effect/ Medication Profile Log daily from October 31st through December 31st of the year long chemotherapy protocol. By December 31st George had learned a set of norms for each side effect he experienced. For example, he knew in the sixth month of therapy when diarrhea occurred more than 7 times in a day that it was not the usual 2 to 4 times a day that he had experienced previously. He also found himself adapting to his side effects and their occurrences. He knew what was normal or abnormal. He began to adjust his expectations for his quality of life. He could predict patterns of his side effects.

As therapy continued George documented eight more side effect experiences. They were flu-like syndrome; lethargy, splitting and scaling of the skin, dry skin, darkening of skin (especially the face), and some hair loss. The other two side effects were watery eyes and peripheral neuropathy which were associated with the long term use of the chemotherapeutic agents. His Neptune Patient Side Effect/Medication Profile Log allowed George to identify these two side effects which might have been ignored if he had not designed and used his side effect monitoring system.

Once George completed his six weeks of therapy and began his weekly regimen of 5-FU and biweekly regimen of levamisole he noticed changes in occurrence, variability and severity of the side effects he had documented previously. Based upon the pattern of these changes George and Martha told us the side effect monitoring system allowed them to make the decision on what days of the week to schedule his therapy. This was an important decision for George and Martha because to have quality time together for themselves and their family was their most important quality of life goal. For this reason they wanted to schedule family time when they could predict less side effects. Data from the side effect monitoring system enabled them to do this.

They chose to receive his biweekly regimen of levamisole on Monday, Tuesday and Wednesday and his weekly dose of 5-FU on Monday at 1600 hours. With the information he recorded in the Neptune Patient Side Effect/Medication Profile Log, he knew the pattern of peak side effects occurred within 12 - 36 hours after a treatment. By scheduling therapy late Monday afternoon at 1600 hours, George would stay home from work on Tuesdays and work Monday, Wednesday - Friday, Saturday, Sunday and Monday morning were the best times of the week because the side effects were at their lowest levels for those days. Thus, in having a
subjective assessment of the peak side effect patterns of severity, George and Martha could enjoy each other, their children, relatives, family and friends more on the weekends. In addition, sometimes, in consultation with their oncologist, they scheduled a drug free week of chemotherapy to attend a special event.

George said, “The side effect monitoring system allowed me to plan my weekly activities; I felt I WAS IN CONTROL in managing my disease and therapy. You just don’t know what that means to have some feeling of control of your life when you’re on chemotherapy.”

George’s basis for patient therapeutic outcome monitoring parallels that required of pharmacists in the provision of pharmaceutical care (8). George learned what to monitor by receiving drug therapy risk management information from physicians, nurses and pharmacists. Brushwood described drug therapy risk management information as that information that allows for the correct use of the medication (7). That information allowed George to monitor therapy from his own perspective as to what was important to him. We learned that George’s side effect monitoring system complemented the clinician’s use of therapeutic outcome monitoring systems such as blood chemistry profiles and identification of the most serious side effects which could cause serious physiological or life threatening problems for the patient.

Alternative Drug Therapy

One of the side effects from the 5-FU therapy was mouth sores. The oncology nurses instructed George to gargle with salt water as often as he could to relieve the pain, doing it 7 - 8 times a day. While George was at home recovering from surgery and starting his weekly chemotherapy it was relatively easy to gargle with salt water. Yet, when he returned to work and began teaching again it was difficult to do. Most offices or classrooms do not have sinks and furthermore gargling in public did not appeal to George. George told a friend at work, who was of Chinese ancestry, about this problem. The very next day he gave George some Chinese dried fruits; e.g., plums, orange slices, etc. The fruit was heavily salted and George sucked on it like a lozenge, it substituted for gargling salt water. George loved the dried fruit and used it frequently, sometimes as many as 20 pieces per day.

At the next appointment with his oncologist George’s blood pressure had increased above the level that was normal for George. George’s oncologist was puzzled and asked George if he knew of any reason why his blood pressure increased? George replied, “I don’t know.” To which his oncologist said, “we’ll have to monitor this.”

On the way home from the clinic visit, George asked Martha if she knew how much sodium was in that dried fruit. She responded that she did not know since it was not on the label of the bag. The next day George asked his friend if he knew how much sodium was in a serving of the dried fruit. He had a bag of plums with a label showing 2,250 mg per every three pieces. If George used 20 pieces of dried fruit a day that increased his salt intake to 13.5 Gm of sodium daily which might raise anyone’s blood pressure. He decreased his use to not more than five a day. At his next clinic visit George’s blood pressure was improved.

When George and Martha related this experience to us they knew the doctors and nurses meant well in telling him to treat his month sores by gargling with salt water. But you could tell that most of them had never done it or did not realize how annoying and difficult it was for a patient to do especially in public. The dried, salted fruit resolved the need to gargle with salt water but contributed to a rise in blood pressure because George used too much of it. We learned from George and Martha that we must be aware of patient’s self-care decisions regarding therapy and how those decisions to use alternative therapy can have pharmacological and physiological effects on the patient, and the provision of care. In the Client-Centered Model of medication management, Chewning and Sleath stressed the importance of learning about a client’s self-care decisions and treatments (6). They suggest health care providers integrate a client’s self-care decisions and behaviors when conducting medication consultations.

Disease and Drug Information Overload

George collected so much written information about his illness and drug therapy that it filled an entire drawer of a standard filing cabinet. The written information came from a variety of sources, for example: medical and pharmacy journals, medical and pharmacology textbooks, the National Cancer Institute, patient medication leaflets, drug package inserts, patient information leaflets about specific side effects, lay press articles, United States Pharmacopeia, and the Internet. In addition to written information, George learned about cancer and treatments from discussions with the nurses, pharmacists and physicians who treated George, and from conversations with colleagues, friends, relatives, cancer patients and family members.

George received most of the information within a month after his diagnosis. If he asked a question a pharmacist, nurse or physician would answer it. Sometimes the clinicians would say, “Here’s a phamplet, read it and if you have any questions please ask us.” Some of the pamphlets contained 10 - 20 pages of text. As the illness episode progressed and treatment decisions had to be made, George and Martha had difficulty in deciding what information was important and useful to them for a specific situation. They observed that once medical personnel gave you written information they assumed you would read it, knew what to read, knew how to use it, and knew how to ask questions about it. This especially was the case with drug information pamphlets. The clinicians at times were so busy, seldom did they have time to review or show George and Martha where they could find the answers to their questions in the pamphlets. Although Martha could help George sort through much of the information, even she had her limitations and became overwhelmed with having to make so many decisions.

George remarked, “Sometimes I just took the information home and used it when I got around to it which sometimes did not occur. Everyone wanted to help us and answer our questions. Yet, I do not think anyone had any idea how much responsibility they placed upon Martha and me to make the best use of written information. It seemed at times we had to make decisions when we had very little time to think about them, there was just so much to think about; e.g. treatments, protocols, medications, finances, the future, etc.”

Consumer behavior researchers have theorized and demonstrated that information overload does occur during consumer decision making, especially if time constraints are placed upon the consumer (9, 10). Malhotra, further suggested if consumers have time constraints and are subject to
information overload they can become confused, frustrated, and make poor decisions (11). Labor, et al., in their study of information overload with written drug information found when patients received too much or too little scope of information they were more likely to be confused and overwhelmed (12).

In a short period of time (see Table I) George and Martha experienced information overload with respect to his illness and while trying to make decisions about treatment. Although George’s health care providers willingly provided information and answered questions, none helped George perform necessary screening, structuring, prioritizing and cueing functions required to efficiently and effectively manage the volume of information to which George and Martha were exposed. The information pertained to drug therapy regimens, and the etiology and prognosis of the illness. Essentially, George and Martha taught themselves how to manage the information overload.

Role of Patient Advocate
We learned from George’s and Martha’s experiences that the role of a patient advocate is multidimensional. For example, for the diagnosis of the illness, the pain management and postoperative colitis problems, Martha immediately assessed George’s deliria and care needs. In the selection of an oncologist Martha asked colleagues and people who would be the best to meet George’s care needs, preferences, attitudes and his values about life. Martha helped George with drug therapy risk assessment and management decisions. She assisted George in managing the information overload especially as it dealt with cancer as an illness. Lastly, Martha, the patient advocate, helped George cope and adapt to his illness, treatment and new life style.

Martha’s advocacy role taught us that a patient advocate can be someone who knows the patient intimately. They have a relationship built upon trust. Martha knew George’s values, preferences, lifestyle and needs. They worked together as a team to solve problems and resolve difficult situations.

Throughout the pharmaceutical care literature researchers and practitioners continue to stress the pharmacist’s role as patient advocate. Schulz and Brushwood further specified the pharmacist’s patient advocate role of providing information that permits patients to assess the risk of drug therapy regimens, and the etiology and prognosis of the illness. “At my last scheduled clinic visit in October 1995, an oncology nurse introduced me to the new oncology fellow. He asked me a specific question, ‘Do you have any side effects with your chemotherapy?’ My immediate response was no but then I looked at Martha, her expression told me that response was not correct. I did have side effects and proceeded to say so. I then shared with the oncology fellow my side effect monitoring system and experiences. Wow! I could not believe that I had responded initially that I had no side effects. I could not believe how much I had learned to adapt and cope with the side effects of therapy.”

Perhaps Leventhal and co-authors’, “Common—Sense Model of Illness,” could be used as a theoretical framework to examined George’s coping and adapting experiences (14). In the model they conceptualize a patient’s perspective of perceptual and conceptual processing systems, representation of illness, treatment and emotional reactions, coping procedures and responses, and appraisals. The model parallels work reported by Schussler who examined coping strategies and individual’s meanings of illness (15). He found the personal attitude a patient has toward a disease and his/her coping mechanisms extends beyond just biomedical factors. People like George and Martha who had the ability to control and accept their disease displayed more of a form of a problem-related coping.

Patient Coping, Adapting and Controlling Experiences
As George progressed through his therapy he shared some intimate thoughts with us. One of those thoughts was dealing with the problem he referred to as “Time Warp.” George stated, “One problem I had was how my mind always traveled at ‘Warp Speed.’ I’m an old Star Trekkie at heart. One second I’d think about my faith, the next my job, the next our family, the next my relatives, the next my wife, the next death, etc. When traveling at ‘Warp Speed’ the content of my thoughts followed no particular pattern. The problem I had was trying to get some control over this experience so I could cope with it.”

George continued, “My major concern with chemotherapy was how it would feel, how is the old body and mind going to adjust, and how it would change my lifestyle. I had to learn some way to cope with it and have some sense of control in my life, that is, not to be at the mercy of the medical staff, the treatment...” George stated, “I had to find a way to monitor my side effects. The medical staff, nurses and pharmacists all gave me information about side effects, yet none of them told me how to monitor my side effects. So I devised a monitoring system based upon the pain management scale I used in the hospital.” George wrote in his diary, “By monitoring my side effects, I was able to determine, after therapy was given, what to expect so I could plan my week and cope with therapy. After a few months of recording my side effects I learned what they were so I no longer had to record them. I knew them and adapted to them. I knew when my bad or down time was but also determined my good time so I could enjoy the family and live a ‘normal life.’ It left me with a great sense of ‘Well Being!’”

In the later months of therapy George had learned to cope and adapt very well to his side effects both psychologically and physiologically. He told us the following experience. “At my last scheduled clinic visit in October 1995, an oncology nurse introduced me to the new oncology fellow. He asked me a specific question, ‘Do you have any side effects with your chemotherapy?’ My immediate response was no but then I looked at Martha, her expression told me that response was not correct. I did have side effects and proceeded to say so. I then shared with the oncology fellow my side effect monitoring system and experiences. Wow! I could not believe that I had responded initially that I had no side effects. I could not believe how much I had learned to adapt and cope with the side effects of therapy.”

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SECTION III: ISSUES FOR PHARMACY EDUCATORS AND PRACTITIONERS
We acknowledge that all patients and their advocates are not like George and Martha. Perhaps as Chewning and Sleath suggest, a patient’s involvement with his/her drug therapy probably lies on a continuum of being very passive to being very active depending upon factors such as: the
situation, a patient’s health status, life style and resources available in the delivery of care (6).

George’s and Martha’s experiences made us think of many issues related to educating and training of pharmacists who provide and practice pharmaceutical care. We pose the issues in a question format. We offer no answers. Instead we use the issues to challenge pharmacy educators to become more aware of a client’s/patient’s perspective in the provision of pharmaceutical care, to think about a client’s needs and preferences from a client’s and client advocate’s perspectives, and to work in collaboration with a client to provide care. The issues are not listed in order of priority or sequenced in specific order for completion.

They are:

• How do we teach pharmacy students and pharmacists about what it means to be a client/patient? To know a client’s/patient’s role? To understand his/her involvement in the diagnosis of an illness?
• How do we teach pharmacy students and pharmacists to establish, nurture and maintain a relationship with a client/patient? With other members of the health care team?
• How do we teach pharmacy students and pharmacists to listen to a client/patient and assess his/her drug related problems and preferences of care?
• How do we teach pharmacy students and pharmacists to involve a client/patient in medication and alternative therapy use and management decisions?
• How do we teach pharmacy students and pharmacists to teach a client/patient how to use drug information properly? To manage information overload?
• How do we teach pharmacy students and pharmacists to develop tools and systems that a client/patient can use to become active participants in monitoring his/her therapeutic outcomes, both clinician significant and client/patient significant?
• Lastly, how do we teach pharmacy students and pharmacists to learn about a client’s/patient’s attitudes, beliefs, needs, preferences and values toward his/her drug therapy, his/her use of alternative therapies and his/her personal assessment of quality of life?

Zola summed it up best when he wrote, “The great majority of people we study and write about neither think of themselves as ‘Patients’ nor are they necessarily functioning in that role when we study them”(16).

CONCLUSION
We have shared some of George’s and Martha’s experiences with colon cancer, they have many more. As pharmacy educators continue to develop and refine Doctor of Pharmacy curricula we ask them to seek answers and solutions to the questions we postulate. Pharmacy educators must incorporate a patient or client perspective about illness, its treatment modalities and quality of life into the curricula and experiential clerkships. Society will judge future contributions of pharmacists upon how well pharmacists attain a more client-centered approach to medication decision making and management in their practices.

EPILOGUE
George still adjusts to lingering long term side effects of the chemotherapy. As a cancer survivor he and Martha live and learn to adapt to the critical medical event that threatened George’s life and changed their lifestyle. We acknowledge the majority of health care practitioners that George encountered, used a more Client-Centered Model approach rather than a Medical-Model approach to George’s and Martha’s medication decision making and management. We also used a research method called introspection, that is, a reliance extensively or almost exclusively upon researchers’ life experiences (2). Consumer researchers group introspective research into five categories: researcher introspection, guided introspection, interactive introspection, synthetic introspection and reflexivity. With each type of introspection we acknowledge the possibility of observer bias in presentation and interpretation of the results. For this paper we used researcher and guided introspection. Therefore, the reader now knows that George and Martha are the authors of this paper.

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