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ORIGINAL ARTICLE

Role of the nurse in patient education and follow-up of people receiving oral chemotherapy treatment: an International survey

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Abstract
Purpose The aim of this study was to explore the nursing role in education and follow-up of patients who were taking oral chemotherapy (CT) and to identify the worldwide gap in patient education about oral CT.
Materials and methods Multinational Association of Supportive Care in Cancer members were invited to participate in a survey on oral CT. Nurse coordinators collected data via a 16-item questionnaire. Respondents totaled 1115 oncology nurses from 15 countries.
Results Findings showed that about half of subjects work in outpatient/ambulatory clinics and had given at least two or more oral CT drugs. Although 52% had some type of guidelines/protocols, 47% reported not having received any

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education about oral CT drugs. While 64% report being involved in patient education, 58% of subjects indicated lack of patient education materials that are specific for oral CT agents. Only 27% stated that they gave all necessary information such as when and how to take the drugs, drug safety and storage, side effects, and symptom management. Reasons for not being involved in oral CT education and follow-up included beliefs that the physician plans the oral CT and gives patients necessary instructions (34%), that nurses only see patients who receive intravenous chemotherapy (16%), that nurses have lack of knowledge about oral agents (15%), and belief that physicians are responsible for patient follow-up. The nurses suggested better education and follow-up of patients to include the written patient education materials (33%) and professional education for nurses (30%).

Conclusions Findings revealed the need for professional education for nurses to ensure comprehensive, consistent patient education and development of written materials for patients receiving oral CT treatment.

Keywords Oral chemotherapy · Nursing · Patient education

Introduction

Oral chemotherapy (CT) treatments are increasingly becoming a part of cancer patient treatment regimens. Approximately 25% of more than 400 antineoplastic drugs currently in the development pipeline are oral agents. Many newer agents are available only in oral form [4, 17]. Traditionally, cancer CT has been administered parentally in a specialized oncology clinic under relatively controlled environment/conditions. The recent introduction of new oral cancer chemotherapeutic agents allows administration to take place outside these controlled settings such as in patient homes, rehabilitation centers, assisted living facilities, and nursing homes [3, 8].

For the patient, oral therapy offers a sense of control over the treatment, reduces interference with daily work and social activities, shortens travel time and costs of going to an infusion clinic, and reduces the discomfort of having an intravenous (IV) line placed for each administration. The use of oral CT has the potential to enhance a better quality of life compared with parenteral CT [1, 17]. Intravenous therapies include risks of extravasation, venous sclerosis, infection, and injection site reaction. In addition, patients with poor venous access may require insertion of a central venous access device, which carries the risk of intraoperative or postoperative complications such as pneumothorax. Long-term use of venous-access devices has been associated with infection, bleeding, and venous thrombosis [4, 17].

Not surprisingly, patient preference for the route of administration favors oral therapeutics. The results of a randomized, crossover trial comparing patient preference for oral capecitabine and 5-fluorouracil/leucovorin regimens in patients with advanced colorectal cancer confirmed that the majority of patients prefer oral to IV therapy [21]. Fallowfield et al. [7] examined the preferences of women with breast cancer regarding endocrine therapy. Through interviews with 208 women with a history of early or stable advanced breast cancer, the investigators found that most women (63%) preferred tablet therapy to injections, although a substantial minority (24.5%) preferred injections. Catania et al. [5] found similar results. They reported that patient felt oral CT could be advantageous in that it would make them less ill and easier to face their illness than traditional IV CT.

Oral agents present new challenges to healthcare professionals in managing cancer treatment such as new or different side effect profiles and toxicities, bioavailability concerns/limitations, and interactions with other drugs as well as with food, nutritional supplements, and herbal remedies [1]. Patient nonadherence to treatment regimens can pose problems, especially when the duration of CT is long [12]. Clinicians need to be aware of these potential problems and take steps to avoid or minimize them to maintain the advantages and efficacy of oral agents [1].

Health professionals cannot accurately predict which of their patients will adhere most closely to their treatment. Even when faced with a potentially life-threatening illness

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such as cancer, it cannot be assumed that the patient will comply with taking their medication. Patients often fail to take their medication as prescribed; disturbingly, almost half the patients currently on oral medication reported forgetting to take their pills from time to time, and 13.1% deliberately chose not to take them at all [7].

Nonadherence to medication among patients treated for breast cancer was studied; of the 131 patients, 55% reported that they did not adhere to medication. The majority of the patients who did not adhere (83.3%) reported this as unintentional because they forgot to take their medication. However, approximately one in six (16.7%) reported intentionally choosing not to take their medication [2]. In this study, researchers also investigated the role of locus of control in adherence and found that younger women were significantly more likely to report not taking their medication, whereas individuals with a higher internal locus of control were more likely to adhere to medication. There is some evidence that adherence is influenced by factors such as age and behavioral characteristics, but the topic of medication adherence is quite complex.

Healthcare providers often assume that their patients are taking medications as prescribed, yet lack of adherence to drug regiments have been reported as a major problem in virtually all medical specialties, patient populations, and healthcare settings [12, 19]. It is known that adherence decreases when long-term therapies are complex [16, 23, 25]. The complexity of the regimen (i.e., number of the drugs/tablets and number of doses per day, taking more than one medication and their sequence) and poor communication from healthcare providers are often mentioned as common causes of nonadherence. Elderly patients with memory disorders are unable to follow complex sets of instructions [19, 23, 25].

People taking oral cancer therapies have a higher incidence of nonadherence because the therapy is self-administered. It then becomes the patient's or family member's responsibility to contact the oncologist's office or outpatient clinic to report problems or adverse effects [17]. Nonadherence with dosing or reporting side effects may occur for a variety of reasons, including misinterpretation of physician's instructions, denial, forgetfulness or confusion, polypharmacy syndrome (taking many oral medications), or distraction by competing priorities (e.g., patient caring for an ill spouse). Other factors that may influence adherence includes cost of the medication, number of doses per day, dosing frequency, and side effects, with nonadherence in direct proportion to an increase in any one of these factors [17, 23, 25].

A study of 69 children with acute lymphoblastic leukemia (ALL) who received oral CT at home revealed that one or more errors occurred with 17 (10%) of the 172 medications that were taken. Twelve of the 17 errors were administration errors (incorrect dosing), and the other five were prescribing errors (miscalculated doses and overdose) [20].

A focus group of adolescents with the ALL study was held to develop an understanding of suboptimal adherence to 6-mercaptopurine therapy in adolescents with ALL. Four broad themes emerged: a desire for normalcy, egocentrism, concrete thinking, and need for parental support. Clinicians need to evaluate cognitive development of their patients and tailor education and treatment plans to their developmental level [15].

Adherence is reported to be better in older, educated, and more affluent patients living in small family groups. Another additional factor that positively affects adherence is the trust and comfort level with the treating physician and healthcare team [2, 17, 19, 25]. While there is no gold-standard measurement for assessing adherence, pill counts and electronic tablet bottles that record each time the bottle is opened have been used to record adherence. Both of these methods have several shortcomings: There was no proof the pill was taken on time or that it was taken at all, only that the pill count was correct or that the bottle had been opened on time [17, 19, 23].

As oral CT becomes more prevalent, the number of patients and caregivers who need to be educated will also increase. The primary responsibilities of oncology nurses are to facilitate patient education, communication, symptom management, and proactive follow-up. It is important to realize that these roles do not end when the patient leaves the clinic [9, 10, 17]. Oncology nurses are uniquely positioned to individualize patient support, which is vital to providing quality patient/family education and side effect management. The amount and quality of patient education, followed closely by the quality of the patient's support system, will directly affect compliance with the treatment regimen. Physicians, nurses, pharmacists, allied health professionals, and family members each have important roles to play in this process [4, 10, 24].

A previous study from Turkey showed that more than 70% of oncology nurses stated they had no guideline/protocol for oral cancer therapy at their workplace. More than 90% reported lack of educational materials, and only half of the nurses reported doing any teaching at all. The reasons they gave for not being involved in oral CT education and follow-up were because the physicians planned oral CT and follow-up of the patients and because of their own lack of knowledge [11]. Nurses and physicians describe the role of the nurse as mostly "giving intravenous CT." Given that the number of oral CT agents is on the rise, nurses must begin to take an active role in patient education and follow-up. The aim of this study is to explore the nurse's role in education and follow-up of patients who are taking oral CT and identify the gap that exists worldwide in education about oral CT.

Materials and methods

The Multinational Association of Supportive Care in Cancer (MASCC) is an international, multidisciplinary organization whose members represent more than 60 countries. MASCC is dedicated to research and education in all aspects of supportive care for patients with cancer. The work of the organization is carried out by its 17 study groups, one of which is the Patient and Professional Education study group [18]. This study group replicated the Turkish study by Kav and Bostanci [11]. The MASCC website and the quarterly e-news were used to invite all interested MASCC members to participate in the study. The call requested that each person participating be responsible for obtaining a sample of 60 nurses in their country who work with cancer patients at different work sites. During Nov 2005–Jan 2007, nurse coordinators from 15 countries collected survey data for a total of 1,115 oncology nurses: Spain (233), Finland (114), Denmark (85), Greece (68), USA (67), UK (66), Australia (64), Lithuania (60), Thailand (60), Serbia (60), China (57), India (57), Palestine (47), Kenya (40), and Israel (37).

The questionnaire consisted of 16 open-ended and multiple-choice questions including demographics (institution, educational status, place of work, position, working years in this clinic, and years in nursing), the most commonly used oral CT agents, availability of policy/guidelines for administration of oral CT agents, nurse education about oral CT drugs, involvement in patient education and information (timing, storage, safety issues, side effects, and symptom management), the reasons for not being involved, and problems/difficulties they faced as nurses. There was one open-ended question asking for the nurses' suggestions to facilitate better education, follow-up, and compliance to treatment of patients receiving oral CT.

Initially, the Turkish version of this questionnaire was translated into English. When necessary, the coordinators translated the English language survey into their respective languages and had it back translated for accuracy. Completed data was submitted to the principal investigator for analysis. Descriptive statistics and Chi-square for significance tests were used for statistical analysis. Findings were accepted as statistically significant at p values of less than 0.05. The open-ended question was grouped into themes and summarized as percentages.

Results

Demographic characteristics of the 1,115 nurse subjects are shown in Table 1. The majority of the subjects were employed in either a university (43.3%) or state hospital (37.7%) setting as a clinical/staff nurse (69.9%). Nearly half of the subjects worked in outpatient/ambulatory clinics, and 57.9% received diploma level education. Most had more than 2 years experience and had given at least two or more oral CT drugs (mostly capecitabine, etoposide, methotrexate, cyclophospamide, melphalan, and temozolomide; Table 1).

Table 1 Nurses' demographics (n=1,115)

Nurses' demographics (n=1,115)	Number	Percent
Institution		
University	483	43.3
State hospitals	421	37.7
Private office practice/outpatient clinic	143	12.8
Private hospital	37	3.3
Other	31	2.8
Position (n=1,095)		
Staff/clinical nurse	766	69.9
Head nurse	125	11.4
Clinical nurse specialist	102	9.4
Research nurse	41	3.7
Nurse practitioner	40	3.7
Educator	21	1.9
Place of work (n=1,064)		
Inpatient	504	47.4
Ambulatory/daily treatment unit	262	24.6
Outpatient	219	20.6
Day treatment and outpatient	65	6.1
Doctor's office	14	1.3
Education (n=1,088)		
Diploma	630	57.9
BSN	245	22.5
Associate (2 years education)	110	10.1
Master	98	9.0
Doctorate	5	0.5
Time worked in this clinic (n=1,112; years)		
<1	100	9.0
2–5	453	40.7
6–10	235	21.1
11–15	137	12.3
16 and over	187	16.8
Time worked in nursing (n=1,111; years)		
<1	17	1.5
2–5	173	15.6
6–10	202	18.2
11–15	209	18.8
16 and over	510	45.9

There is a significant difference in nurses' education, availability of guidelines/protocols, educational materials, responsibilities for patient education, and follow-up for patients receiving oral CT among the countries. Although 52% of the subjects reported having some type of guidelines/protocols, half of the nurses reported not having received any education about oral CT drugs. More than half of the subjects indicated a lack of patient education materials that are specific for oral CT agents. This is especially true, not only for respondents living in develop-

ing countries but also respondents from Spain and Greece (Table 2).

Although 64% of the respondents indicated being involved in patient education (Table 3), only 302 of them (27%) reported giving information about when and how to take the drug, drug safety and storage, side effects, and symptom management. Reasons for not being involved in oral CT education and follow-up included the belief that the physician plans the oral CT and gives patients the necessary instructions, that nurses only see patients who receive IV CT, that nurses have a lack of knowledge about oral agents, and believe that physicians are responsible for follow-up of patients (Table 4).

Table 5 outlines the responses given by the nurses to the question concerning the difficulties and their suggestions to facilitate better education and follow-up of patients on oral CT drugs. The difficulties identified by nurses included not knowing the side effects and symptom management for oral therapies. Not being part of the healthcare team who see patients taking oral therapies was perceived as a problem. Suggestions given by respondents most often included the desire for written materials for teaching patients, professional education about oral CT, collaboration/teamwork, development of guidelines, counseling, development of tools to improve patient's compliance, nurse-led clinic for oral CT, and phone follow-up (Table 5).

Research nurses and nurses who worked in outpatient departments reported being more involved with oral CT drugs by providing patient education and follow-up and seeking education/information on oral CT. Staff nurses who worked on inpatient units and had less than 5 years experience reported lack of education/information about oral CT. These findings were statistically significant at $p < 0.05$ (Table 6).

Discussion

This is the first multinational study that explores the current role and needs of nurses in patient education and follow-up for patients receiving oral CT treatment.

There is a significant difference between the countries regarding education, availability of guidelines/protocol, patient educational materials and involvement in patient education, and follow-up for patients receiving oral CT. As can be seen in Table 2, nurses from European countries such as Lithuania, Denmark, UK, Finland, and Serbia were more involved and have received professional education on oral CT. It is interesting to note that nurses from Thailand indicated that they are involved in patient education and follow-up but reported having no professional education, guidelines, or patient educational materials. As can be expected, nurses in developing countries reported a lack of resources in professional and patient educational materials. This is understandable given the limited resources in all aspects of healthcare in these countries.

When administering IV CT, oncology nurses are in a prime position to provide patient teaching because the patient

Table 2 Participating countries, number of nurses per country (in descending order), education on Oral CT, availability of guidelines/protocol, educational materials, attendance of patient education, and follow-up

Country	Number	Education on oral CT (n=1,100)		Guidelines/protocol for oral CT administration (n=1,107)		Attendance of patient education and follow-up (n=1,109)		Educational materials (booklets, drug sheets; n=1,091)	
		Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Australia	64	79.3	20.7	64.5	35.5	67.3	32.7	68.3	31.7
China	57	66.7	33.3	40.7	59.3	71.9	28.1	16.7	83.3
Denmark	85	78.6	21.4	78.8	21.2	92.8	7.2	65.4	34.6
Finland	114	89.5	10.5	75.2	24.8	89.0	11.0	86.6	13.4
Greece	68	28.4	71.6	36.8	63.2	36.8	63.2	6.0	94.0
India	57	35.1	64.9	45.6	54.4	25.0	75.0	17.9	82.1
Israel	37	43.2	56.8	51.4	48.6	56.8	43.2	50.0	50.0
Kenya	40	20.0	80.0	20.0	80.0	20.0	80.0	10.0	90.0
Lithuania	60	78.0	22.0	95.0	5.0	96.7	3.3	61.7	33.3
Palestine	47	10.6	89.4	17.0	83.0	48.9	51.1	12.8	87.2
Serbia	60	75.0	25.0	78.3	21.7	83.3	16.1	65.0	35.0
Spain	233	27.9	72.1	36.1	63.9	47.2	52.8	16.1	83.9
Thailand	60	–	100.0	–	100.0	100.0	–	–	100.0
UK	66	81.8	18.2	83.3	16.7	89.4	10.6	75.8	24.2
USA	67	54.1	45.9	63.1	36.9	49.3	50.7	74.2	25.8
Total	1115	51.2	48.8	52.8	47.2	64.5	35.5	41.5	58.5

Table 3 Education on oral CT and sources of education (n=1,115)

	Number	Percent
Education on Oral CT		
Yes	563	51.2
No	537	48.8
Sources of education (n=563)		
In-service education	432	36.1
Scientific meeting (congress, conference, etc.)	323	26.9
Book/journal/newsletter	268	22.3
Internet	116	60.7
Other (drug rep/company 18; part of clinical trials 4; during university education 2)	60	5.0
Total	1,199[a]	100.0

[a] Some items may have multiple answers

and family members are in the infusion area for a period of time. The situation is different for patients receiving oral agents as treatment for their cancer. In clinics and office-based oncology practices, nurses primarily are stationed in the infusion rooms and may not see patients who are not on IV therapy. These patients are more apt to receive their prescriptions and medication information directly from their oncologist or pharmacist and not have access to an oncology nurse. Nor are these patients likely to see an oncology nurse during follow-up visits. The usual CT education visit or patient-teaching session provided to patients starting IV CT may be not scheduled when a patient is on oral CT. However, just as patients who receive IV CT, patients who receive oral CT need to be educated [9].

It is known that understanding the way the medication works, how it should be taken, expected side effects and their management, and how to contact the oncology staff for guidance will result in patients remaining on the therapy for more cycles with fewer side effects that require dose interruption or modification [9, 10, 14, 17]. Patient and family education may be the most important factor in successful outcomes of patients receiving oral CT. Yet, in this study, only 27% of the respondents (n=302) stated that the patients received information such as when and how to take the medicine, drug safety and storage, side effects, and symptom management. To ensure that the patients on oral cancer therapies have the benefit of being well informed requires that nurses assume responsibilities for patients' education, symptom management, and proactive follow-up. Nurse educators are challenged to provide clinical nurses with the training and support necessary to enhance adherence of patients taking oral CT at home.

New treatments, patient preference, and the economic realities of cancer care delivery challenge physicians, nurses, pharmacists, and cancer center administrators to restructure their activities to provide cost-effective and high-quality care. A survey that was conducted in the USA of National Cancer Institute-designated comprehensive cancer centers showed that in current practices in use of oral CT, most centers' physicians shared responsibility with other health professio-

Table 4 Role of the nurse in patient education and follow-ups (n=1,115)

	Number	Percent
Attendance of patient education and follow-ups (n=1,109)		
Yes	715	64.5
No	394	35.5
Information given on oral CT (n=715)		
1—Timing (dose and schedule)	629	20.1
2—Storage (secure and appropriate)	547	17.5
3—Side effects and symptom management	662	21.2
4—Not crush tablets or open capsules	498	15.9
5—Safety precaution when taking the drug	356	11.3
6—Safety precautions after taking the drug	394	12.6
7—Other (drug interaction, lab works, contact number)	39	1.4
Total	3,125[a]	100.0
The reasons of not being involved to oral CT education and follow-ups (n=394)		
Physician plans oral CT and gives necessary instructions	394	33.9
Nurse only see patients who receive IV chemotherapy	186	16.1
Nurse may not know about the specifics of oral CT drugs	179	15.4
Physician follows-up the patients	170	14.6
Nurse may not have enough time	111	9.5
Pharmacist will give necessary information	70	6.1
Other	52	4.4
Total	1,162[a]	100.0

[a] Some items may have multiple answers

Table 5 Nurses' difficulties and suggestions to facilitate better education and follow-up of patients and their compliance to the treatment (n=1,115)

	Number	Percent
Nurses' difficulties (n=1,073)		
I did not have any problem	292	19.5
Side effect and symptom management	323	21.7
Usually patient sees only physician, not he nurse	307	20.5
Explaining the safety issues	255	17.1
Explaining how to take the drugs	224	15.1
Other	91	6.1
Total	1,492[a]	100.0
Nurses' suggestions (n=394)		
Patient education and written educational material	182	33.7
Nurse education/training /workshop/continuing education	160	28.8
Physician–nurse collaboration/communication/teamwork	48	8.6
Development of guidelines/protocols or policy and procedures for Oral CT administration and management of side effects	40	7.2
Patient counseling/nurse consultant	38	6.8
Tool to help patients to take (diary, video/DVD, chart, checklist, calendar)	27	4.8
Nurse-led clinic/specific clinic	25	4.5
Given/having enough time for patient education	16	2.8
Phone follow-up	15	2.7
More nursing staff	4	0.1
Total	555[a]	100.0

[a] Some items may have multiple answers

Table 6 Comparison of nurses' providing patient education and follow-ups and information on oral CT with nurses' demographics

Nurses' demographics	Providing patient education and follow-ups		p value	Receiving education/information on oral CT		p value
	Yes (%)	No (%)		Yes (%)	No (%)	
Place of work						
Day treatment unit	63.7	36.3	$p<0.001$	52.3	47.7	$p<0.001$
Inpatient	59.4	40.6		45.4	54.6	
Outpatient	79.0	21.0		60.7	39.3	
Doctor's office	61.5	38.5		71.4	28.6	
Education						
Diploma	63.0	37.0	$p>0.05$	51.7	48.3	$p<0.001$
Associate (2 years education)	74.5	25.5		69.1	30.9	
BSN	66.9	33.1		44.2	55.8	
Master/doctorate	65.0	35.0		66.0	34.0	
Working years in clinic						
<1	62.0	38.0	$p>0.05$	45.4	54.6	$p<0.05$
2–5	63.0	37.0		49.9	50.1	
6–10	64.8	35.2		51.5	48.5	
11–15	69.1	30.9		56.3	43.7	
16 and over	71.0	29.0		62.9	37.1	
Position						
Staff/clinical nurse	63.0	37.0	$p<0.01$	49.9	53.1	$p<0.001$
Head nurse	63.1	36.9		61.0	39.0	
Clinical nurse specialist	74.5	25.5		67.3	32.7	
Research nurse	85.4	14.6		72.5	27.5	
Nurse practitioner	65.0	35.0		61.5	38.5	
Educator	76.2	23.8		71.4	28.6	

Percentages are based on the row total

nals for educating patients about oral CT [22]. Respondent's indicated that nurse practitioners (60%), nurses (81%), and pharmacists (95%) were also responsible for educating patients about oral CT use and safety. Only a third of the centers provided special training or certification for those who educate patients about these oral medications. Nearly a quarter [10] of centers had no formal process for monitoring patients' adherence. Few of the safeguards in routine use of infusion CT have been adopted for oral CT, and currently, there is no consensus at these centers about safe medication practices for oral CT [22].

Strategies for enhancing adherence may include improvement of clinician–patient relationships, educational strategies such as one-to-one counseling, written information with verbal reinforcement, involvement of the patient in the discussion of treatment goals, reduction in the complexity of the treatment regimen, tailoring the treatment to the patient's lifestyle, use of reminders, encouragement of family support, monitoring of adherence, and provision of feedback to the patient. There is no evidence that one method improves compliance better than another. Combinations of educational and behavioral strategies have shown better effect than single approaches [23]. Eliciting patients' beliefs is important before providing information, thus patients' perceptions may be corrected or reinforced. Other practical adherence aids include organizers and reminders such as blister packs, calendars, dosage counters, special containers, dosage forms, controlled delivery, and microprocessors [10, 17, 24].

In this study, nurses' suggestions included having better professional education and follow-up of patients, providing written materials for teaching patients and nurse education/training, collaboration/teamwork, development of guidelines, counseling, providing tools to help patients to take/remind their medication, a nurse-led clinic, and phone follow-up.

A pilot study investigated whether daily pill boxes can help simplify oral anticancer regimens to make adherence easier, when compared with conventional pill bottles [13]. Although results did not demonstrate that the use of daily pill boxes improved patient adherence, many patients preferred and were more satisfied with this packaging method and thought that the daily pill boxes were more helpful in reminding them to take their medications [13]. Furthermore, all patients were given a diary card to complete to accurately track their CT usage and that served as an additional memory aid that helped patients remember to take their medication.

Implications for oncology nursing

Oncology nurses have already established extended roles in nurse-led breast cancer clinics, radiotherapy clinics, symptom control in lung cancer, and delivery of home-based intravenous CT [6, 14]. The evidence for the efficacy of these initiatives is encouraging [6]. In a recently published article from the UK, reports that results of an audit of a nurse-/pharmacy-led clinic for patients receiving capecitabine suggested that a nurse-/pharmacy-led clinic for the provision of home-based oral CT is safe, effective, and acceptable to most patients [14]. In this study, measuring patient satisfaction highlights the important role nurses and pharmacists have in the active management of colorectal cancer. Further studies may show that the nurse-/pharmacy-led clinic may provide effective support and education for patients receiving capecitabine as part of their cancer treatment and may be used as a model in other centers and with other types of cancer, where oral CT is used in cancer treatment [14].

Empowering nurses to be able to follow with patients who are prescribed oral CT, at clinic visits or through telephone contacts, may facilitate patient monitoring and patient/family satisfaction and may help promote patient adherence. The development of institutional guidelines for oral CT administration and side effect management is another possible contribution of the healthcare professional in ensuring optimal patient care [24].

Conclusions

This is the first multinational study that explores the current roles and differences of nurses' needs for professional education regarding managing and teaching patients and families about oral CT. Oral CT has opened a new era for the cancer therapy that requires health care professionals to consider revising their approaches in patient management to achieve the highest quality of patient care. Patients who take complex drug regimens at home without professional healthcare supervision may lead to serious consequences unless accurate patient education and regular follow-up are observed to ensure patient adherence and safety. Many patients perceive a better quality of life with the use of oral therapies [5, 17]. There may also be significant emotional benefit if patients perceive themselves as partners in the therapeutic process [9, 10, 17].

Until recently, oral CT treatment played only a minor role in the overall treatment plans. Little, if any, attention has been given to the nurse's role and responsibility for oral medications that was evident in the results from the Turkish study. It can be said that the worldwide results shows similar outcomes. These two studies have revealed the need for nurse education to ensure comprehensive and consistent patient education and development of written materials for patients receiving oral CT treatment. However, research is needed to identify the gaps that may exist in the role of other healthcare professionals who are involved in management of the patient receiving oral therapies.

Results of this study have provided the rationale for MASCC's Education Study Group to propose a project to develop a clinical teaching tool for use with patients receiving oral CT. The goal of this project is to improve the oncology nurses' knowledge base about their role and responsibility in caring for patients receiving oral CT medications. To meet this outcome, a short, simple clinical teaching tool is being developed that includes a checklist of items to cover for patients receiving oral CT, along with instructions and a form nurses can use to monitor treatments, patient adherence, patient calls, and other issues. The 15 study coordinators will be invited to disseminate the tool within the oncology nurse community in their home countries. It is intended that nurses use this tool in the initial patient education phase, thus helping them to teach patients in a consistent and comprehensive way.

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References

1. Aisner J (2007) Overview of the changing paradigm in cancer treatment: oral chemotherapy. Am J Health-Syst Pharm 64(9 Suppl 5):S4–S7
2. Atkins L, Fallowfield L (2006) Intentional and non-intentional non-adherence to medication amongst breast cancer patients. Eur J Cancer 42(14):2271–2276
3. Bartel SB (2007) Safe practices and financial considerations in using oral chemotherapeutic agents. Am J Health Syst Pharm 64(9 Suppl 5):S8–S14
4. Bedell CH (2003) A changing paradigm for cancer treatment: the advent of new oral chemotherapy agents. Clin J Oncol Nurs 7 (Suppl 6):5–9
5. Catania C, Didier F, Leon ME, Sbanotto A, Mariani L, Nolè F, Leida E, Rocca A, De Pas T, Goldhirsch A (2005) Perception that oral anticancer treatments are less efficacious: development of a questionnaire to assess the possible prejudices of patients with cancer. Breast Cancer Res Treat 92(3):265–272
6. Corner J (2003) The role of nurse-led care in cancer management. Lancet Oncology 4(10):631–636
7. Fallowfield L, Atkins L, Catt S, Cox A, Coxon C, Langridge C, Morris R, Price M (2006) Patients' preference for administration of endocrine treatments by injection or tablets: results from a study of women with breast cancer. Ann Oncol 17(2):205
8. Goodin S (2007) Advancing the safe and appropriate use of oral chemotherapy agents. Am J Health Syst Pharm 64(9 Suppl 5):S3
9. Hartigan K (2003) Patient education: the cornerstone of successful oral chemotherapy treatment. Clin J Oncol Nurs 7(6):21–24
10. Hollywood E, Semple D (2001) Nursing strategies for patients on oral chemotherapy. Oncology 15(Suppl 2):37–40
11. Kav S, Bostanci H (2006) Role of the nurse in patient education and follow-up of people receiving oral chemotherapy treatment in Turkey. Support Care Cancer 14(12):1252–1257
12. Kelly A, Agius CR (2006) Improving adherence to endocrine therapies: the role of advanced practice nurses. Oncology (Nurse Edition) 20(10 Suppl 7):50–54
13. Macintosh PW, Pond GR, Pond BJ, Leung V, Siu LL (2007) A comparison of patient adherence and preference of packaging method for oral anticancer agents using conventional pill bottles versus daily pill boxes. Eur J Cancer Care 16(4):380–386
14. MacLeod A, Branch A, Cassidy J, McDonald A, Mohammed N, MacDonald L (2007) A nurse-/pharmacy-led capecitabine clinic for colorectal cancer: results of a prospective audit and retrospective survey of patient experiences. Eur J Oncol Nurs 11:247–254
15. Malbasa T, Kodish E, Santacroce SJ (2007) Adolescent adherence to oral therapy for leukemia: a focus group study. J Pediatr Oncol Nurs 24(3):139–151
16. McDonald H, Garg A, Haynes B (2002) Interventions to enhance patient adherence to medication prescriptions. J Am Med Assoc 288(22):2868–2879
17. Moore S (2007) Facilitating oral chemotherapy treatment and compliance through patient/family-focused education. Cancer Nurs 30(2):112–122
18. Multinational Association of Supportive Care in Cancer. Available at http://www.mascc.org/. Accessed on August 24, 2007
19. Partridge AH, Avorn J, Wang PS, Winer EP (2002) Adherence to therapy with oral antineoplastic agents. J Natl Cancer Inst 94:652–661
20. Taylor JA, Winter L, Geyer LJ, Hawkins DS (2006) Oral outpatient chemotherapy medication errors in children with acute lymphoblastic leukemia. Cancer 107(6):1400–1406
21. Twelves C, Gollins S, Grieve R, Samuel L (2006) A randomised cross-over trial comparing patient preference for oral capecitabine and 5-fluorouracil/leucovorin regimens in patients with advanced colorectal cancer. Ann Oncol 17(2):239–245
22. Weingart SN, Flug J, Brouillard D, Morway L, Partridge A, Bartel S, Shulman LN, Connor M (2007) Oral chemotherapy safety practices at US cancer centres: questionnaire survey. BMJ 334:407–411
23. Vermeire E, Hearnshaw H, Van Royen P, Denekens J (2001) Patient adherence to treatment: three decades of research. A comprehensive review. J Clin Pharm Ther 26(5):331–342
24. Viele CS (2007) Managing oral chemotherapy: the healthcare practitioner's role. Am J Health Syst Pharm 64(9 Suppl 5):S25–S32
25. Vlasnik JJ, Aliotta SL, Delor B (2005) Medication adherence: factors influencing compliance with prescribed medication plans. Case Manager 16:47–50 (March/April)