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How variable is our delivery of information? Approaches to patient education about oral chemotherapy in the pediatric oncology clinic

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Abstract

In pediatric patients with acute lymphoblastic leukemia, adherence to oral chemotherapy relies largely on a parent's comprehension of the drug's indication and administration guidelines. We assessed how pediatric oncology providers educate families about oral chemotherapy. We conducted a cross-sectional survey of 68 physicians and nurses from nine institutions in the Dana-Farber Cancer Institute Acute Lymphoblastic Leukemia Consortium. The inter-individual approach to patient education is variable and may consist of handouts, treatment calendars and

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discussions. The extent of teaching often varies depending on a provider's subjective assessment of a family's needs. Twenty-five percent of providers suggested standardizing patient teaching. When developing educational models, care teams should consider approaches that 1) objectively identify families in need of extensive teaching, 2) designate allotted teaching time by nursing staff during clinic visits and 3) maintain the variation and dynamism that informs a successful provider-patient relationship.

Keywords

pediatric; leukemia; adherence; cancer care delivery; patient education

Introduction

In the field of pediatric oncology today, the roles of healthcare providers continue to shift and evolve as treatment regimens include more oral chemotherapy agents.(Place et al., 2015) Providers are not only responsible for writing prescriptions, but are also responsible for effectively educating patients and their caregivers about administration guidelines and treatment regimens. Based on this premise, the inherent challenge for providers is related to identifying the optimal way to deliver this critical information to each individual family.

Ensuring accurate adherence to prescribed treatment regimens is a challenge in every field of healthcare, including pediatric oncology where home oral chemotherapy is incorporated into many treatment regimens. Administration of oral chemotherapy at home is a highly complex and often labor-intensive endeavor for patients and their caretakers. It is estimated that some children with cancer may take upwards of ten medications at home per day.(Kondryn, Edmondson, Hill, & Eden, 2011) Standard treatment for pediatric acute lymphoblastic leukemia (ALL) requires two years of pharmacologic therapy. The Continuation phase of therapy lasts 70 weeks and rests on a backbone of oral chemotherapeutics, including 6-mercaptopurine (6MP) and dexamethasone. During this treatment phase, parents are responsible for administering 6MP to their children for 14 consecutive days every three weeks, which can directly impact the success, or failure of the child's treatment. The potential impact of oral chemotherapy non-adherence on patient outcomes was demonstrated in a landmark study published by Bhatia et al., (2012). In this study, investigators assessed adherence to 6MP in a large cohort of pediatric ALL patients being treated on a Children's Oncology Group (COG) treatment protocol. Investigators observed that less than 95% adherence to 6MP was associated with a 3.1-fold increase in relapse risk. Despite this, they found that up to 30% of the study population was non-adherent to oral chemotherapy, thus highlighting both the danger and magnitude of this problem (Bhatia et al., 2012).

Published studies have identified medication administration errors in 10 to 40% of pediatric children < 18 years old who are receiving oral chemotherapy at home (Taylor, Winter, Geyer, & Hawkins, 2006). In the medical literature, there are numerous studies linking provider-patient teaching to therapy adherence, particularly with regard to oral chemotherapy (Pritchard, Butow, Stevens, & Duley, 2006; Tebbi, 1993). Accurate and consistent adherence to home medications is influenced by patient-, provider- and systems-

related factors (Brown & Bussell, 2011). Healthcare providers are responsible for educating patient caregivers about both administration guidelines and about the necessity of the medications prescribed. Without effective teaching, patient caregivers are at risk of erroneously administering home medications or of not administering them at all.

Here we report the results of a cross-sectional survey aimed at examining the way physicians (attending and fellows), nurse practitioners (NP), registered nurses (RN) and physician assistants (PA) all working in a pediatric oncology clinic with expertise in ALL, communicate and re-enforce treatment information about oral medications to patients and families during the continuation phase of pediatric ALL therapy. We hypothesized that there would be high variability in the provider-driven education practices surrounding oral chemotherapy during the Continuation phase treatment for ALL. We also hypothesized that care providers would suggest moving towards standardizing the educational approach as a means of improving the efficacy of our teaching and care delivery.

Materials and Methods

This study was approved by the Institutional Review Board at Columbia University Medical Center. We conducted a survey of healthcare providers directly involved in the care of children (ages 1 – 18 years) undergoing treatment for pediatric ALL. The study population included: physicians, NPs, PAs and RNs from participating institutions. All medical providers were chosen for participation by their site-specific study principal investigator in order to ensure accurate respondent recruitment at each participating hospital. The privacy rights of human subjects were observed and completion or submission of the survey was considered implicit consent from each medical provider.

Survey Instrument

A 10-item questionnaire was developed over the course of three months and was administered online via SurveyMonkey™. The medical literature routinely identifies three key aspects of patient education that can directly contribute to medication adherence and these themes formed the basis of our survey questions (Haskard, DiMatteo, & Heritage, 2009; Landier et al., 2011; Pritchard et al., 2006; Walsh, Kaushal, & Chessare, 2005). Themes included (though were not limited to): 1) who provides education and teaching (continuity of care and the provider-patient relationship), 2) how is information provided (handouts, electronic, interactive approaches) and 3) when and with what methods is information given and re-enforced. Survey questions developed for this study were focused around addressing the above aspects of education and cancer care delivery. Nine questions were closed with pre-coded response options (multiple choice answers) and one question was an open question inquiring about improving care delivery. At the time of survey distribution, all participants were sent an email explaining the aims of the study as well as the plans for use of the information gathered. Prior to widespread distribution, survey questions were distributed to the leukemia team at New York Presbyterian-Columbia for review and revision. Minor modifications were made. A list of the survey questions is presented in Appendix I.

Results

Participants

The survey was sent to 90 pediatric ALL healthcare providers at nine medical institutions and a total of 68 people responded (75%). (Table I) Breakdown of participants was as follows: Attending physician (N=24, 36%), RN (N=21, 31%), clinical Fellow (N=13, 19%), NP (N=9, 13%) and PA (N=1, 1%). Out of 68 providers who completed the whole survey, 35 participants (N=24, 51%) responded to the free-text question at the end.

Survey Questions and Responses

Continuity of care—Pediatric patients undergoing therapy for ALL are seen by multiple members of the medical team at each clinic visit. All patients are seen by a primary attending and up to 70% are also seen by a primary fellow or NP. Forty-five percent of respondents reported that for each child, the primary medical providers are the same individuals who provide teaching about medication administration guidelines. In contrast, 44% of respondents reported that these primary providers are only “sometimes” the same individuals who are providing teaching. Ten percent of respondents stated that a patient’s primary provider is often not the same person who is providing the education about oral chemotherapy. Fifty-eight percent of respondents stated that RNs alone are responsible for patient education about home medications during clinic visits.

Delivery of information: How and when (Table 2)—The extent and frequency of education about oral chemotherapy was assessed in part two of the survey. One hundred percent of respondents stated that a “discussion” about dexamethasone and 6MP is included in the education process. These discussions were variable as some providers emphasized the role and function of 6MP and dexamethasone while others emphasized dosing guidelines only. Between 40 and 50% of respondents reported that they review information to varying extents “depending on the family.” Seventy-nine percent of respondents stated that the “majority” of their patients understand what is being taught, 13% stated that all of their patients understand and 7% stated that they were “unsure” about how well patients and their caregivers understand what medical providers are teaching about oral chemotherapy. Seventeen percent of respondents answered that during these conversations they do not actively identify the primary caregiver who is responsible for administering oral chemotherapy at home. Nurse practitioners in general were more likely than fellows or attending physicians to regularly provide written or typed calendars to their patients.

Care delivery—The final survey question elicited suggestions from providers about ways to improve the education process (Table 3). Both providers (including Attending physicians, PAs and Fellows) and nurses suggested that during each clinic visit there should be designated time for teaching by NPs and RNs. With regard to standardization of the educational approach, 25% of all survey participants responded that there is a need for standardization of teaching materials, including multilingual handouts and formalized schedules. Finally, respondents suggested that prior to beginning their clinical duties, incoming trainees should receive formal training about effective methods of teaching and communication.

Discussion

Though brief, this survey provides important information about care delivery within the pediatric oncology clinic. Additionally, it provides information about providers' approaches to patient education surrounding oral chemotherapy during ALL treatment. We found that, while all patients are seen by an assigned attending physician, more often, the direct teaching about oral chemotherapy regimens and administration guidelines comes from NPs and RNs. Contrary to our initial hypothesis, only a quarter of survey respondents seemed to favor a standardized teaching approach for patients and their families. Rather, many of the respondents, nurses and doctors alike, seemed to advocate for more protected teaching time, specifically by NPs and RNs.

In a meta-analysis exploring provider-patient communication and medication adherence, Zolnierrek et al., 2014 investigated the overall impact of provider-patient interactions on patient therapy adherence. This investigation revealed that superior physician communication was positively correlated with patient adherence across 106 different studies ($p < 0.001$) (Zolnierrek, 2014). Our survey revealed that in many cases, the primary healthcare providers seeing the patients at each visit are often not the same providers who are providing detailed education and administration guidelines related to oral chemotherapy administration. Whether the impact of this plays out with the patient feeling more or less supported and connected to their medical team is not addressed in this survey and thus cannot be accurately inferred. In the pediatric oncology clinic, care teams include both physicians and nurses and other ancillary staff members, all of whom contribute to a patient's medical and healthcare needs. Much of the medical literature about oral chemotherapy education focuses on the role of nurses in this setting (Bedell, 2003; Hartigan, 2003; Kav et al., 2008). Bedell and colleagues suggest that oncology nurses play a key role in observing, teaching and monitoring patients receiving oral chemotherapy. Similarly, our survey revealed that RNs and NPs are frequently providing much of the follow-up and re-enforcement to patients and families (Bedell, 2003).

Approach to teaching

Our study demonstrates that there is variability in provider-driven education practices about oral chemotherapy. No single treatment site had a concrete curriculum for patient education and thus, delivery of information varied by individual provider rather than by medical institution. Despite inherent variability, one quarter of providers suggested that a standardized approach to patient/parent-education could improve our delivery of information and, by extension, our delivery of care.

Closed-loop communication

In a recent publication, Walsh et al (2013) sought to identify the spectrum and incidence of home medication errors in pediatric patients receiving oral chemotherapy. Investigators performed a prospective study at three sites in which they compared medication administration instructions with the associated medication-taking practices at home. Investigators found that the majority of errors (63%) occurred during active drug administration and were often in the form of failure to appropriately adjust medication doses

as instructed by the medical team (Walsh et al., 2013). They also found that home medication administration errors were frequently a result of miscommunication on two fronts: first, between physicians and patient/parents, and second, between parents and other caregivers at home. In this study, 82% of clinicians and 56% of family members were unaware of the medication errors that had occurred. In their conclusion, physician reviewers postulate that more seamless communication about medications between parents and the medical team might have prevented 36% of home medication errors. Our survey revealed that more often than not, medical providers are not identifying the caregivers responsible for administering medication at home. Additionally, we found that written information and calendars are not consistently provided. Theoretically this might lead to miscommunication at home, especially if there are multiple patient caregivers, and thus, should be further explored.

Patient comprehension

Studies suggest that medical providers overestimate patient/parent understanding of medical information being given (McPhillips et al., 2005). While parents and caregivers may frequently display adequate understanding of oral chemotherapy prescriptions and instructions during clinic visits they still remain at risk of erroneously administering these medications at home (Gandhi et al., 2005; Lerner, Jehle, Janicke, & Moscati, 2000). As suggested by our survey results, effective delivery of clear and consistent information is reliant, in part on the medical provider's assessment of each parent's educational needs. It can be challenging for medical providers, however, to accurately identify which families may require more extensive teaching in order to ensure that they have clear understanding of oral chemotherapy regimens (Yin et al., 2014). Our survey indicated that 40 to 50% of providers reported offering more in-depth and focused teaching about oral chemotherapy "depending on the family." Though providers are actively assessing the cognitive ability of their parents/patients, they are doing so in a subjective and primarily informal manner.

Conclusion

This study identified the variability with which healthcare teams are providing education to patients about oral chemotherapy. While there is rarely a member of the care team who is actively designated an "educator," we did find that nurses, both RNs and NPs, are key participants in the process of teaching and re-enforcing information to our patients and families. Pritchard et al (2006) suggest that adherence to oral chemotherapy directly depends on the healthcare provider's ability to effectively emphasize its absolute importance and simultaneously equip a parent with clear and straight-forward guidelines to facilitate adherence (Pritchard et al., 2006) (Bedell, 2003). Much of the literature about medication adherence in pediatric populations suggests that, on a systemic level, standardization of teaching improves understanding and by extension, improves compliance (Goldzweig et al., 2013; Mullen & Green, 1985; Mullen, Green, & Persinger, 1985). With regard to education about oral chemotherapy, however, standardizing our teaching approach may only be part of the solution. While 25% of our respondents suggested that standardized teaching methods might be of benefit for some of our pediatric ALL patients, double this number suggested that a more varied approach to education is frequently being employed. Both physicians and

nurses reported modifying their educational practices based on an assessment of each family's needs and capacity. This re-enforces the notion that effective teaching for one family is not necessarily effective teaching for another. It is conceivable that the variability with which we deliver information is a critical component of the teaching process that should not be overlooked. When developing new educational models, care teams must consider approaches that not only ensure clear and consistent information delivery but that also allow for the necessary variation and dynamism that informs a successful provider-patient relationship.

In the future, we plan to assess the effectiveness of the educational process from the standpoint of patients and their caregivers in order to develop prospective educational interventions to improve communication and care delivery for patients and families undergoing treatment for ALL.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

- Bedell CH. A changing paradigm for cancer treatment: the advent of new oral chemotherapy agents. *Clinical Journal of Oncology Nursing*. 2003; 7(6 Suppl):5–9. DOI: 10.1188/03.CJON.S6.5-9 [PubMed: 14705494]
- Bhatia S, Landier W, Shangguan M, Hageman L, Schaible AN, Carter AR, ... Wong FL. Nonadherence to oral mercaptopurine and risk of relapse in Hispanic and non-Hispanic white children with acute lymphoblastic leukemia: a report from the children's oncology group. *Journal Clinical Oncology*. 2012; 30(17):2094–2101. DOI: 10.1200/JCO.2011.38.9924
- Brown MT, Bussell JK. Medication adherence: WHO cares? *Mayo Clinic Proceedings*. 2011; 86(4): 304–314. DOI: 10.4065/mcp.2010.0575 [PubMed: 21389250]
- Gandhi TK, Bartel SB, Shulman LN, Verrier D, Burdick E, Cleary A, ... Bates DW. Medication safety in the ambulatory chemotherapy setting. *Cancer*. 2005; 104(11):2477–2483. DOI: 10.1002/cncr.21442 [PubMed: 16245353]
- Goldzweig CL, Orshansky G, Paige NM, Towfigh AA, Haggstrom DA, Miake-Lye I, ... Shekelle PG. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Annals of Internal Medicine*. 2013; 159(10):677–687. DOI: 10.7326/0003-4819-159-10-201311190-00006 [PubMed: 24247673]
- Hartigan K. Patient education: the cornerstone of successful oral chemotherapy treatment. *Clinical Journal of Oncology Nursing*. 2003; 7(6 Suppl):21–24. DOI: 10.1188/03.CJON.S6.21-24
- Haskard KB, DiMatteo MR, Heritage J. Affective and instrumental communication in primary care interactions: predicting the satisfaction of nursing staff and patients. *Health Communications*. 2009; 24(1):21–32. DOI: 10.1080/10410230802606968
- Kav S, Johnson J, Rittenberg C, Fernandez-Ortega P, Suominen T, Olsen PR, ... Clark-Snow R. Role of the nurse in patient education and follow-up of people receiving oral chemotherapy treatment: an

international survey. *Supportive Care Cancer*. 2008; 16(9):1075–1083. DOI: 10.1007/s00520-007-0377-x

Kondryn HJ, Edmondson CL, Hill J, Eden TO. Treatment non-adherence in teenage and young adult patients with cancer. *Lancet Oncology*. 2011; 12(1):100–108. DOI: 10.1016/S1470-2045(10)70069-3 [PubMed: 20580606]

Landier W, Hughes CB, Calvillo ER, Anderson NL, Briseno-Toomey D, Dominguez L, ... Bhatia S. A grounded theory of the process of adherence to oral chemotherapy in Hispanic and caucasian children and adolescents with acute lymphoblastic leukemia. *Journal of Pediatric Oncology Nursing*. 2011; 28(4):203–223. DOI: 10.1177/1043454211409582 [PubMed: 21653911]

Lerner EB, Jehle DV, Janicke DM, Moscati RM. Medical communication: do our patients understand? *American Journal of Emergency Medicine*. 2000; 18(7):764–766. DOI: 10.1053/ajem.2000.18040 [PubMed: 11103725]

McPhillips HA, Stille CJ, Smith D, Hecht J, Pearson J, Stull J, ... Davis RL. Potential medication dosing errors in outpatient pediatrics. *Journal of Pediatrics*. 2005; 147(6):761–767. DOI: 10.1016/j.jpeds.2005.07.043 [PubMed: 16356427]

Place AE, Stevenson KE, Vrooman LM, Harris MH, Hunt SK, O'Brien JE, Silverman LB. Intravenous pegylated asparaginase versus intramuscular native *Escherichia coli*-asparaginase in newly diagnosed childhood acute lymphoblastic leukaemia (DFCI 05-001): a randomised, open-label phase 3 trial. *Lancet Oncology*. 2015; doi: 10.1016/S1470-2045(15)00363-0

Pritchard MT, Butow PN, Stevens MM, Duley JA. Understanding medication adherence in pediatric acute lymphoblastic leukemia: a review. *Journal of Pediatric Hematology Oncology*. 2006; 28(12):816–823. DOI: 10.1097/01.mph.0000243666.79303.45

Taylor JA, Winter L, Geyer LJ, Hawkins DS. Oral outpatient chemotherapy medication errors in children with acute lymphoblastic leukemia. *Cancer*. 2006; 107(6):1400–1406. DOI: 10.1002/cncr.22131 [PubMed: 16909415]

Tebbi CK. Treatment compliance in childhood and adolescence. *Cancer*. 1993; 71(10 Suppl):3441–3449. [PubMed: 8490895]

Walsh KE, Roblin DW, Weingart SN, Houlahan KE, Degar B, Billett A, ... Mazor KM. Medication errors in the home: a multisite study of children with cancer. *Pediatrics*. 2013; 131(5):e1405–1414. DOI: 10.1542/peds.2012-2434 [PubMed: 23629608]

Yin HS, Dreyer BP, Moreira HA, van Schaick L, Rodriguez L, Boettger S, Mendelsohn AL. Liquid medication dosing errors in children: role of provider counseling strategies. *Academy of Pediatrics*. 2014; 14(3):262–270. DOI: 10.1016/j.acap.2014.01.003

Zolnieriek CD. An integrative review of knowing the patient. *Journal of Nursing Scholarship*. 2014; 46(1):3–10. DOI: 10.1111/jnu.12049 [PubMed: 24119235]

Appendix I. Survey Questions

SURVEY AIM: To assess the variability in provider-driven education about oral chemotherapy for patients and their families during the Continuation phase of treatment for pediatric ALL

1. Please select the option below that best describes your current position

- a. Attending
- b. Fellow
- c. Nurse Practitioner
- d. Physician Assistant
- e. Registered Nurse

2. For a given patient being seen in the outpatient setting, who is/are the main medical provider(s) responsible for history, physical exam, lab review and prescription writing during each clinic visit?

- a. Attending alone
- b. Fellow with attending supervision
- c. NP with attending supervision
- d. PA with attending supervision
- e. Other (please specify)

3. Is/are the providers identified in the above question the same people who provide patient education (ie. dosing, calendar, duration) regarding home administration of oral chemotherapy? (Please select all that apply)

- a. Yes
- b. No
- c. Sometimes

4. If different from above, who are the providers responsible for patient-education during clinic visits? (Please select all that apply)

- a. Attending
- b. Fellow
- c. Nurse Practitioner
- d. Physician Assistant
- e. Registered Nurse
- f. Other (please specify)

5. At the initiation of Consolidation II and Continuation phase, how is information about oral chemotherapy administration provided to patients and caregivers (Please select all that apply)

- a. Drug information printed summaries
- b. Direct discussion with patient/caregiver
- c. Other (please specify)

6. How do you assess parent/caregiver understanding of information given by the medical team?

- a. Ask patient/caregiver to describe the information they were given
- b. No formal assessment
- c. Other (please specify)

7. Oral Dexamethasone: Once a patient is in his/her Continuation phase of therapy, how frequently do you (please select one best option)

	Once at the beginning of Continuation	At the start of every new cycle	Every few months	Varies depending on the family	Never	I do not personally review
Review the fact that in this setting, Dexamethasone is a chemotherapeutic agent?	☐	☐	☐	☐	☐	☐
Identify the caregiver responsible for medication administration at home?	☐	☐	☐	☐	☐	☐

Inquire about missed medication doses? ☐ ☐ ☐ ☐ ☐ ☐

8. Mercaptopurine (6-MP): Once a patient is in his/her Continuation phase of therapy, how frequently do you (please select one best option)

	Once at the beginning of Continuation phase of therapy	At the start of every new cycle	Every few months	Varies depending on the family	Never	I do not personally review
Review the fact that 6-MP is a chemotherapeutic agent?	☐	☐	☐	☐	☐	☐
Identify the caregiver responsible for medication administration at home?	☐	☐	☐	☐	☐	☐
Review administration guidelines for 6-MP (ie. dairy consumption and daily dose-timing)?	☐	☐	☐	☐	☐	☐
Inquire about missed medication doses?	☐	☐	☐	☐	☐	☐

9. In your opinion, how well do you think your patients and their caregivers understand the importance of oral chemotherapy in the context of their overall treatment plan?

- a. All of my patients/caregivers understand
- b. Majority of my patients/caregivers understand
- c. Minority of my patients/caregivers understand
- d. Unsure

10. If an educational intervention were to be developed in order to improve understanding of oral chemotherapy administration by patients/caregivers, what materials or teaching methods (frequency, aims) might prove useful? What suggestions do you have regarding approach to patient education and optimization of health literacy in your patients and their caregivers?

Table 1

List of Participating Institutions with Percent of Survey Participants

Study Site	Total Participants N = 68 (%)
Dana Farber Cancer Institute (Boston, MA)	25 (37%)
New York Presbyterian-Columbia University Medical Center (New York, NY)	18 (27%)
Montefiore Medical Center (New York, NY)	7 (10%)
San Jorge Children's Hospital (San Juan, PR)	1 (1%)
Inova Fairfax Hospital (Falls Church, VA)	2 (2%)
Hasbro Children's Hospital (Providence, RI)	7 (10%)
CHU de Quebec (Quebec City, Quebec)	3 (5%)
CHU Sainte-Justine, University of Montreal (Montreal, Quebec)	1 (1%)
McMaster University (Hamilton, Ontario)	4 (7%)

Table 2

Delivery of Information: Survey responses about **how** and **when** providers educate patients and families about oral chemotherapy.

	Percent of Survey Respondents
Discussion about therapy	100%
Emphasis on role and function of oral chemotherapy (during discussion)	30%
Emphasis on dosing guidelines only (during discussion)	70%
Printed information handouts are included at the time of discussion	82%
Printed calendars provided	20%
Discussions take place at the start of every three-week cycle	40–50%
<i>How do you assess patient/parent comprehension?</i>	
Ask for “read back” after teaching	70%
No formal assessment	30%
<i>Do you think that parents and caregivers understand what is being taught?</i>	
Majority of caregivers understand	79%
All caregivers understand	13%

Table 3

Free-Text Answers: New Education Initiatives

Themes and Concepts for Teaching Initiatives	Example
Development of education materials	Information sheets in multiple languages Standardized calendar
Interactive approach to education	Formal, scripted discussion templates with read-back of understanding from patient Teaching on non-chemotherapy days Scheduled teaching time during each week 1 visit Videos Online education portal, parent self-assessments, visualizations
Prescriptions and labeling	Multi-lingual prescription labels and administration instructions Pill boxes
Teaching by RNs	Allotting time for RNs to provide teaching in order to establish a basis for teaching and re-teaching every few months Set time for RN teaching at each clinic visit prior to checkout in order to review plan and re-enforce discussion
Approach to assessing patient understanding: How and when?	One-on-one teaching weekly during the first three cycles of oral chemotherapy Survey or assessment of adherence barriers every 3 to 6 months Medication logs/diary
Teaching the teachers	Formal training for new trainees and fellows regarding patient-education