Optimizing patient education of oncology medications

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Disclosures

- Conflicts of interest: none
- Research sponsorship and funding: none

Learning objectives

1. To explore patients’ perspectives of optimal oncology medication education provided to patients at the Nova Scotia Health Authority (NSHA), Central Zone
2. To describe and quantify the patient perspective of optimal oncology medication education across the province of Nova Scotia
3. To explore healthcare professionals’ perspectives of optimal oncology medication education

Background

Oncology patient education

May include:
- Diagnosis
- Prognosis
- Monitoring required
  - Bloodwork
  - Imaging
- Treatment
  - Surgery
  - Radiation
- Medication
- Side effects
  - Fever
  - Nausea and vomiting
  - Safety information
  - Storage
  - Chemotherapy precautions
- Supportive care
  - Medication
  - Hydration

Background

Oncology patient medication education

Progressively more important due to:
- Complexity of cancer treatments
- High-risk patients
- Serious side effects
- Aging population
- Improved prognoses
Standards of Practice for Oncology Pharmacy in Canada

The oncology pharmacist should counsel cancer patients and their family members:
- To address any concerns about the drug therapy,
- To provide specific drug information required for safe and appropriate drug therapy,
- To offer suggestions for the prevention or management of potential side effects and
- To promote compliance.

Oncology outpatient education at the Nova Scotia Health Authority (NSHA)

Provision of patient education at NSHA:
- Oncologists at diagnosis
- Nurses in clinics or chemotherapy treatment room
- Possibly seen by a pharmacist during treatment

Barriers to provision of patient education by pharmacists:
- Limited oncology pharmacist staffing
- High volume of patients and chemotherapy orders

Oncology research in the NSHA pharmacy department

- National survey of pharmacist-provided patient education (n = 64)
  - 50% of pharmacists spent up to 25% of their time providing direct patient care
  - Not all patients seen by a pharmacist
  - 1/3 of pharmacists see < 25% of patients receiving iv therapy

Building our knowledge: Oncology pharmacy research plan

Optimizing patient education of oncology medications: A patient perspective
- Tessa E Lambourne, Laura V Minard, Heidi Deal, Jennifer Pitman, Megan Rolle, Debbie Saultier, Joanne Houlihan

Development of a new education model to increase patient education by pharmacists.
Oncology patient education: Existing literature

Describes:
- General information and communication needs
- Methods of education
- Benefits of patient education
- Oral chemotherapy medication education
- Little literature exists looking specifically at oncology patient medication education needs and preferences
- Quantitative methodology has been the primary means of exploring information needs of patients with cancer
- Little qualitative research done to probe more deeply into the patient perspective


Exploring the patient perspective

Benefits:
- Shared decision making
- Greater patient satisfaction
- Improved sense of control
- Better communication
- Reduced anxiety and fear

Patients frequently report that they receive inadequate information and feel that their education needs have not been met

Patient Prefer Adherence. 2012;6:765-72
Psychooncology. 2013;22(3):490-8
Patient Educ Couns. 2011;83(3):367-74
Support Care Cancer. 2014;22(1):129-34

Research Objective

To explore patients’ perspectives of optimal oncology medication education provided to patients at the NSHA, Central Zone

Methods

Study Design
- Qualitative study
- Focus groups

Focus Group Moderation
- Moderator + assistant
- Introductions, topic overview and ground rules
- Participant information package
- Informed consent, demographic data form and pledge of confidentiality

Study Population
- Medical, gynaecological or hematological oncology adult outpatients at NSHA who:
  - have received ≥ 75% of their prescribed chemotherapy protocol
  OR
  - have completed at least three cycles of chemotherapy
  OR
  - are currently receiving second or greater line of chemotherapy
  OR
  - have completed treatment up to three months prior to screening
- Chemotherapy was broadly defined to include treatment with immunotherapy, targeted, or cytotoxic agents
Methods
Recruitment
- Eligible patients invited to participate via the patient information sheet provided by nurses in the chemotherapy treatment room
- Telephone call to schedule focus group time slot
- Confirmation letter, information package, informed consent form, and demographic data form sent to patients by mail and/or email

Methods
Focus group questioning route
- Short, open-ended questions
- Pilot tested
Examples
1. Tell us about your experience receiving education on your chemo drugs
2. Is there a time during your course of treatment that would have been better to receive education on your chemo drugs?
3. What is your opinion on scheduling a separate appointment to meet with the hospital pharmacist to receive education on your chemo drugs?
4. How could education on your chemo drugs have been improved?

Methods
Transcript-based analysis
- Focus groups audio recorded and transcribed
- NVivo 11 software
Field notes & debriefing session
- Moderator + assistant moderator
Thematic analysis: constant comparative method
- Coding: identifying similar words or phrases
- Categorizing: group related codes
- Development of themes: group related categories

Results
Three focus groups (FG) held in January 2017 at the Victoria General hospital
- 6-8 participants per group
- n=21 oncology patients
- Age range: 51-82 years (mean age: 65 years)

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Participants (n=21) n (%)</th>
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</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (57 %)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (43 %)</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
</tr>
<tr>
<td>College or university</td>
<td>15 (71 %)</td>
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<tr>
<td>High school or junior high school</td>
<td>6 (29 %)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
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<tr>
<td>Married</td>
<td>13 (62%)</td>
</tr>
<tr>
<td>Other*</td>
<td>8 (38 %)</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Living with spouse/family/friend/other/alone</td>
<td>15 (71 %)</td>
</tr>
<tr>
<td>Living alone</td>
<td>6 (29 %)</td>
</tr>
</tbody>
</table>

*Other: divorced, common-law, single, widowed

<table>
<thead>
<tr>
<th>Clinical characteristics</th>
<th>Participants (n=21) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Solid tumour</td>
<td>15 (71 %)</td>
</tr>
<tr>
<td>Hematological</td>
<td>6 (29 %)</td>
</tr>
<tr>
<td>Route of chemotherapy</td>
<td></td>
</tr>
<tr>
<td>Oral</td>
<td>9 (43 %)</td>
</tr>
<tr>
<td>Intravenous</td>
<td>21 (100 %)</td>
</tr>
<tr>
<td>Mean number of chemotherapy cycles (range)</td>
<td>18 (4-33)</td>
</tr>
</tbody>
</table>
Results: Four major themes

**Theme #1: Preparing for what lies ahead**

*Participant B1:*
"And you know the Doctor could have even told me but in the initial meeting with her, like I went blank when she started telling me all this stuff. It's just like overwhelming-so much information"

Category: Readiness to receive information
Codes: Difficulty processing and retaining information, Not ready for so much information at once

**Participant B4:**
"They don’t tell you about any side effects, I’m not talking about all side effects, I’m talking about the most common maybe, what to look for? I’ve had occasions where we didn’t go to the hospital right away and I had a pulmonary embolism and I laid down for a day and a half at home and when I decided to go to the hospital the Doctor was like: why didn’t you come and did you know that this is dangerous?"

Category: Gap in provision of patient education
Codes: Lack of education on side effects, Importance of receiving education on side effects, Alarm symptoms and who to contact

**Theme #2: Bridging the information gaps**

*Participant A2:*
"I think the more information you get and the more frequently it’s given and throughout the whole process like- at various stages throughout it was reiterated that this is what you’re getting and this is the side effect"

*Participant A3:*
"Reiteration! That’s the word right there"

Category: Gap in continuity of patient education
Codes: Reiteration, Continued education, Difficulty processing and retaining information
Theme #3: Understanding the education needs of the patients

Participant B4: “I’ve been coming to the hospital for nine years and I’ve had three sets of treatments... and I wish there was an initial meeting with the pharmacist to say this is the plan for the drugs”

Category: Sources of information
Codes: Desire to meet with the pharmacist, Desire to receive some information upfront

Participant B3: “To receive that [education] as the medication is making its way through your body maybe wasn’t the best time”

Category: Education timing and setting
Codes: Desire to receive some information upfront, Feeling vulnerable

Top 5 items that patients felt were most important to know about their chemo drugs

1. Importance of receiving information on side effects
2. How and when to take the medication
3. How the drug works
4. Drug interactions
5. Alarm symptoms and who to contact
6. Effects of treatment on lifestyle
7. Storage, handling and disposal of the medication
8. Education around anti-nausea drugs
9. Information on insurance, drug coverage and cost of the medication

Theme #4: Experience within the healthcare system

Experience within the healthcare system

Interactions with healthcare professionals
Willingness to ask questions
Patient satisfaction
Financial implications
Theme #4
Experience within the healthcare system

Participant C2:
“If pharmacy could somehow get on the floor the same as the nurses are and maybe visit people and if somebody does have a question, you know, they’re more willing to ask if you’re right there with them”

Category: Willingness to ask questions
Codes: More willing to ask questions if you’re right there on the floor, You need that personal touch, Establish a relationship and develop rapport

Discussion
Preparing for what lies ahead
- Patients are overwhelmed and anxious
- Readiness to receive information at diagnosis?
- Setting expectations

Bridging the information gaps
- Importance of reiteration and continued education
- Emphasis on side effects
- Lack of contact with the pharmacist

Understanding the education needs of the patients
- Combination of different sources of information
- Different learning styles, individually
- Desire for quantitative information
- Timing of education
- Some information upfront

Interactions with the healthcare system
- Willingness to ask questions
- Costs of treatment

Research Objective
- To describe the patient perspective of optimal oncology medication education across the province of Nova Scotia

Optimizing patient education of oncology medications: A quantitative analysis of the patient perspective
Kristin Kaupp, Samantha Scott, Laura V Minard, Tessa E Lambourne

Methods
Study design
- Quantitative online and paper survey
- Hosted on the Opinio survey software
- January 26th – April 30th 2018

Study population
- Adult (≥ 18 years of age)
- Medical, gynaecological and hematological oncology outpatients
- Receiving IV chemotherapy from a hospital within NSHA
Methods

Questionnaire development
- Lambourne et al
- Standards of Practice for Oncology Pharmacy in Canada
- Clinical expertise
- Assessed for face validity and readability

Questionnaire distribution
- All NSHA hospitals that administer outpatient IV chemotherapy were asked to participate
- Onsite staff provided eligible patients with a patient information sheet inviting them to participate

Results
- 168 responses
  - 142 complete
  - 26 incomplete + 3 excluded

Timing of education

<table>
<thead>
<tr>
<th>Percentage of patients</th>
<th>At diagnosis/before treatment</th>
<th>First treatment</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preferred</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Frequency of education

<table>
<thead>
<tr>
<th>Percentage of patients</th>
<th>Continuously</th>
<th>Once</th>
<th>At a couple treatments</th>
<th>At each treatment</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Preferred</td>
<td></td>
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</tbody>
</table>

Types of information

| Received | | | |
|------------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| 1. Side effects | | | |
| 2. Who to contact if you experience a serious side effect | | | |
| 3. How to manage side effects | | | |
| 4. How and when to take their medications | | | |
| 5. How the medications work | | | |
| 6. Prevention of side effects | | | |
| 7. Education around supportive therapies | | | |

Most important to know

| Most important to know | | | |
|------------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| 1. How the medications work | | | |
| 2. Side effects | | | |
| 3. How to manage side effects | | | |
| 4. Who to contact if you experience serious side effects | | | |
| 5. How and when to take the medications | | | |
| 6. Prevention of side effects | | | |
| 7. Expected effect of medications on the disease | | | |
Discussion

- This province-wide survey showed that oncology patients in NS are generally:
  - Satisfied with their oncology medication education
  - Comfortable asking questions
- The education patients received appears to align with their education preferences

Discussion: Pharmacist involvement

- Currently most education is provided by nurses and physicians
- Many patients are NOT seen by a hospital pharmacist
- 93% medical oncology
- 35% haematology oncology
- 93% gynaecology oncology
- 84% medical oncology
Discussion: Pharmacist involvement

Current education model:
- Primarily nurses and physicians
- Many patients NOT seen by a hospital pharmacist
- 84% medical oncology
- 93% gynaecology oncology
- 35% hematology oncology

Hematology patients significantly more likely to see a pharmacist

For consideration in the future:
- 30% of patients would like the opportunity to schedule an appointment and 43% would like to receive follow-up from a hospital pharmacist
- Patients with a higher level of formal education

Previous research
- Little research has focused on the HCP perspective in providing oncology medication education
- Prior to implementing a new education model at NSHA multidisciplinary team perspectives should be investigated

Research Objectives
To explore the perspectives of HCPs working in oncology at NSHA regarding:
1. What they believe to be ideal oncology medication education
2. The timing of when they believe education should be provided
3. The role they believe each team member has in providing information to patients

Exploring the perspectives of healthcare professionals in delivering optimal oncology medication education
Allison Lively, Laura V Minard, Samantha Scott, Heidi Deal, Tessa Lambourne, Jennifer Giffin

Multidisciplinary oncology education
- Multidisciplinary oncology education is perceived to:
  - Enhance patient and healthcare professional (HCP) relationships
  - Improve patient education
  - Improve adverse effect monitoring

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2. The timing of when they believe education should be provided
3. The role they believe each team member has in providing information to patients
Methods

Study design
- Qualitative
- One-on-one interviews

Study population
- Physicians, nurses, and pharmacists practicing in medical, gynaecological, or hematological oncology at NSHA Central Zone

Recruitment
- All eligible HCPs at NSHA were emailed to participate
- Interested participants scheduled an interview with the principal investigator

Methods

- Semi-structured interviews
- Open-ended questions
- 20-30 minutes
- Information package and informed consent
- Participant information: "profession" and "discipline"
- Pledge of confidentiality

Data analysis
- Audio-recorded and transcribed
- Transcript-based analysis using Nvivo 11 software
- Thematic analysis

Results

15 interviews conducted February – April 2018
- 5 physicians
- 4 nurses
- 6 pharmacists
- Setting: Bethune Building and Victoria General Hospital

Results: Themes

- Delivery of oncology medication education
- Facilitating the patient learning process
- Multidisciplinary approach
- Barriers to the HCP in providing education

Theme 1: Delivery of oncology medication education

Delivery of oncology medication education

- Prioritization of chemotherapy drug information
- Modes of education delivery
- Presentation of information
- Timing of education

Pharmacist participant
"I like simplicity, I like all one stop shopping, one piece of paper, two at the most, that says it all in less paper"
Category: Presentation of information
Code: Condensed information
Theme 2: Facilitating the patient learning process

Facilitating the patient learning process

- Reassurance
- Reinforcement of education
- Individualized education
- Understanding patient needs

Nurse participant: “How many times I’ve heard [patients] say they would sooner hear [information] too many times than not enough. Too many times versus not enough is so much better”

Category: Reinforcement of education
Code: Repetition of chemotherapy education

Pharmacist participant: “I think there should be a time between diagnosis and when treatment is starting that’s an opportune window to start [education] because any time you provide information that’s near the diagnosis it’s going to be overwhelming and needs repeating for patients”

Category: Understanding patient needs
Codes: Time to digest, Patients get overwhelmed

Theme 3: Multidisciplinary approach

Multidisciplinary approach

- Collaboration among HCPs
- Communication among HCPs
- Distinct roles of HCPs

Pharmacist participant: “I mean ideally it would be nice if there was more collaboration than there currently is. So, we kind of - right now I feel that we all kind of work in our own little silo and we all have different information to give [patients]”

Codes: Collaborative approach, Different perspectives of HCPs in delivering education

Physician participant: “Yeah auxiliary people outside the cancer centre, like family doctors as well, should know about this because they’re often the first people to hear about toxicities”

Code: Communication with auxiliary HCPs

Theme 4: Barriers to the HCP in providing education

Barriers to the HCP in providing education

- Lack of knowledge of other HCPs
- Current resources
- Avoiding misleading information
- Needs of the HCP
Theme 4: Barriers to the HCP in providing education

Nurse participant: “I mean in an ideal world, if we’re not busy and myself, as the nurse, has time to sit and go over everything, and I have [the patient’s] undivided attention, and things aren’t beeping off and I am not getting up and going and doing things and coming back to start over or pick up where I left off.”

Category: Current resources
Code: Hectic environment, Time constraints

Physician participant: “So yeah I haven’t thought too much in depth who does education cause I know what I want to do as long as someone is doing the other things”

Category: Lack of knowledge of other HCPs
Code: Assumptions

Discussion

- Individualization of education
- Barriers exist
- Opportunities for education to be repeated
- Decreases information overload
- Patient coping mechanisms impacted after diagnosis

Also emphasized by patients

Role for all HCPs in the delivery of oncology education
- Community practitioners
- Distinct roles of each HCP
- Current barriers to provision of patient education
- Hectic work environment
- Assumptions/lack of knowledge of roles of other HCPs

Summary

- Content in themes supported in literature
- Novel patient needs identified
- Previously unknown barriers to HCPs in delivery of patient education were identified
- Overlap between the patient and HCP perspectives
  - Integrate findings into new education model
  - Increased pharmacy involvement
  - Patient-pharmacist appointment?
  - Follow-up?

Implications for practice

This research will:
- Facilitate the provision of meaningful education to patients
- Promote multidisciplinary teamwork in oncology
- Promote pharmacist clinical activities in oncology departments to optimize drug therapy for patients
- Guide the strategies that will be used to improve the delivery of oncology medication education at NSHA
  - new education resources/models

Improve patient care
Thank you!

Pharmacy residents
- Tessa Lambourne
- Kristin Kaupp
- Allison Lively

Co-investigators
- Samantha Scott
- Heidi Deal
- Jen Giffin
- Joanne Houlton
- Jennifer Pitman
- Megan Rolle
- Debbie Soulier

Participants
- Patients
- HCPs
- Oncology pharmacists and nurses across NS
- Susan Bowles
- Gillian Donald
- Claudia Harding
- Heather Neville
- Pharmacy Residency Committee

Questions?

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