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Medicine education in a pediatric oncology setting: What can we do better?

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ABSTRACT

Background: When patients feel more involved in their care, there tends to be a higher rate of adherence and improved health outcomes. This can be more difficult to achieve in pediatric care since children have varying levels of medicine comprehension and parents are an integral component of the child's learning.

Objectives: This study aimed to determine the satisfaction of children and families being treated for cancer with their medicine education and determine areas for improvement.

Methods: Semi-structured interviews were conducted over six months (2016/2017) with families and children with cancer, ages 7 to 19 years, ($n = 6$) and healthcare providers ($n = 9$) to assess the current method of medicine education delivery.

Results: Families reported increased stress and anxiety levels at the time of diagnosis, negatively impacting their information retention. Patients, families, and healthcare providers reported inconsistent education delivery, including varying amounts of information throughout the treatment and inconsistencies between providers, such as medication names. Parents mentioned a desire for a more consistent and standardized delivery of medicine education, which was found to be helped by a pharmacist-led approach. Receiving supplemental written materials to support verbal education helped with learners' understanding and information retention. Ensuring that the parents are comfortable and familiar with the medicines is a significant component of medicine teaching in pediatric care because they are often responsible for the child's medications and their children see them as a trusted source of information. Ensuring parents' needs are met translates to improved medicine adherence for children with cancer.

Conclusion: Medicine education should occur sometime post-diagnosis once the patient/family has had time to adjust and the anxiety lessens. Medicine education should be given as consistently as possible by a recurring member of the care team, ideally the pharmacist. The learners' ability to understand and retain information should be individually assessed to determine the delivery of medicine education. Motivating and empowering learners, including children, through frequent medicine encounters could help improve adherence, patient health outcomes, and quality of life and make them more self-managing throughout life.

1. Introduction

In medicine and the management of illnesses, it is essential to use a patient-centered approach including shared decision-making (SDM). SDM is a collaborative approach between a healthcare provider and patient used to help the patient reach an evidence-informed medical decision that aligns with their personal views and beliefs.¹ Although there is a limited amount of literature surrounding SDM and its effects on patient health outcomes, satisfaction, and medication adherence and knowledge, several available studies and reviews suggest that an SDM

approach to care may help increase these patient factors.²⁻⁴ While this method is less challenging to implement in the care of adults, the patient/child is often deliberately disregarded in pediatric care, and it becomes a parent-clinician interaction.⁵

Diagnoses of chronic conditions in children have been on the rise for the past several decades. As of 2022, in the United States, it is estimated that roughly 2 in 5 school-aged children (6 to 17 years old) are living with at least one chronic health condition.⁶ It is also estimated that in 2023, nearly 15,000 American and 1000 Canadian children and adolescents will be diagnosed with cancer.^{7,8} Based on our previous 2011

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study, *What do children with cancer know about their medications?* In which 16 patients, ages 6 through 18 years were interviewed, 73% of the children reported that the physician directed medication education solely to the parents, and 64% said that they were only sometimes or never present in the room while this occurred.⁹ These results are supported by a review conducted by Coyne (2008), where they found that many kids also felt neglected, mitigated, or as though their wishes were not elicited.⁵ Children are often overlooked for several reasons, mainly because they are usually not engaged in discussion, they are distracted by their tablets/phones (as noted by some health care providers during this study), or because it is difficult for the healthcare provider to accurately assess the child's competency and ability to comprehend the information.^{5,10}

Although it may be challenging to assess each child's competency since they develop at different rates and a mature nine-year-old may be more competent than an immature 14-year-old, it is still essential to include them in discussions surrounding their conditions. Including children in decision-making can help to increase their health literacy, which has been shown to increase knowledge of disease and medication, patient satisfaction, treatment adherence, and health-related quality of life.¹¹

Counselling pediatric patients offers another level of challenges because it is more than just a conversation between a patient and healthcare professional but also the parents or caregiver, making it more of a family-centered approach. Often, the child is not self-administering the medications, so everyone involved in the circle of care must be involved in the education on what and when medications are to be given, how they are to be administered, and why they are important. If all caregivers and involved parties are not included, they are more likely to make independent decisions outside of the healthcare professional's recommendations or instructions. Families are more likely to adhere to the prescribed regimen when they feel as though they have been active decision-makers and have a greater understanding of their child's medications and condition.¹⁰ Caregivers are of utmost importance in providing medicine education to their children as they are trusted by them. Healthcare professionals need to work with the parents as well as the children to improve medicine education, child engagement, and ultimately, adherence.

To address the gaps in medicine education of children with cancer and their families, this study qualitatively assessed family and child reports of what they felt improved their understanding of medicine and what hindered learning. These findings may provide healthcare providers and oncology pharmacists with strategies and techniques to help children and their family members learn about their medicines and perhaps improve adherence.

2. Methods

This study was a needs assessment that implemented an interpretive qualitative design. Qualitative data were collected from all participants and stakeholders and organized to explore the differences between what children with cancer at the IWK were learning and what they should have learned.

The participants included: healthcare providers, children undergoing active treatment or follow-up care at the IWK Health Centre and their families, as well as stakeholders who had an interest in IWK pediatric oncology medicine education. Exclusion criteria included those who were not able to provide consent for themselves and those who are unable to speak English.

Children or family members were not approached for recruitment at the time of diagnosis as this is a period when they are overwhelmed. As well, only those families who were identified by staff to be appropriate were approached. All children were included who could participate.

This study included 9 healthcare providers and 6 children (7–19 years) and their families. Families were approached no sooner than three months after the time of diagnosis (average one year) to allow time

to adjust to their child's new diagnosis. Patients who could not provide consent for themselves and could not speak English were excluded from this study.

Over 6 months (2016/2017), a qualitative methodologist conducted interviews to assess the current method of educating children and families with cancer about their medications at the IWK. Interviews were held with participants during clinic visits to collect data related to stakeholder's interests about the medicine education program (interview guide in supplemental material).

Consent was obtained by all participants. All information received throughout this study was kept confidential and coded. The data were stripped of all possible identifiable information and transferred to NVivo for management and analysis.

Data were analyzed using NVivo and based on Strauss and Corbin's (1990) technique of Constant Comparative, in which the data is read and coded across questions and participants. Persistent codes and code groups became themes, which provided the results.

Ethics approval: This study was approved by the IWK REB.

3. Results/themes

3.1. Stress/anxiety limit retention

A significant and common theme found during this study was that patients and families are often very overwhelmed at the time of diagnosis. All healthcare professionals interviewed in this study agreed that "anxiety impedes their understanding of the information that we give them." During the initial diagnosis consultation, physicians often give the patients lots of information about the available treatment options at a level deep enough to obtain informed consent in the hopes of starting treatment as soon as possible. Patients and families are told, "you need all that first, then you should ask me". The ability to comprehend or retain any of the information is almost always hindered when given a large amount of information during a time of heightened anxiety and stress; many patients and parents in this study mentioned that their learning during this initial stage was minimal or nonexistent for at least the 24 h following diagnosis. One parent remembered thinking, "this is just too much information for me, I am overwhelmed with this."

3.2. Pacing information

In this study, one physician noted that patient education typically begins as *telling* in a 90:10 physician-led to patient-led conversation. "It is a graded thing because there is so much that you have to discuss with patients [and] families." Over the following weeks, as patient anxiety and stress start to settle, these conversations become more balanced, more of a 50:50 or 60:40, and it is at this point that patients begin to understand their medicines. One physician commented that the initial information is "too much for the family" because of the sheer volume. Ultimately, his preference was to "give small amounts."

As the distribution of medication calendars occurs while patients prepare to go home, one pharmacist in this study stated that her time for education is often limited and that the patient's attention is often elsewhere, so there is a higher focus on enforcing adherence than education.

3.3. Supporting materials

Another theme related to the value of written information and documentation tools. One mother commented, "I keep everything in the one binder ... we do add to it as her drugs change." She found it very useful because "the information was always there."

One nurse added that the "printed information we give them is sometimes wordy." Regardless of the information that is given to families, ultimately, all healthcare educators tell patients and family members to "ask a lot of questions."

3.4. Consistency/standardization

Health care providers do not always include all members of the family when relaying medical information, “I find ... if there’s a doctor that’s more used to dealing with her mother ... that doctor deals with her and I get left aside ... sometimes the focus is not on both parents ... [just] the one they are most comfortable with.”

Information given to families also tends to be inconsistent. Medicine education interactions tended to be “completely different”. Some patients and families do not understand but are completely adherent, saying just “tell us what we need to do.” While this does not apply to all, some patients and families are more keen to learn everything pertaining to their care than others, like this one mother and daughter. “Me and [my daughter] both need to know ... she can tell you what meds she takes in a day ... it so habitual now ... she can even tell you what medicine she doesn’t want to take.” One patient gave the following advice: “ask a lot of questions.”

Feeling a lack of understanding, one parent stated, “basically they put her on medication, told us why, told us how to administer it, that was it.” Another parent, unsure about her daughter’s blood pressure medication, stated, “she is supposed to take them so she’s going to take them [but] maybe she’s taking this blood pressure med, for nothing. ... right now we just sit here and trust ... I don’t like that idea... I need to know... she needs to know ... if she is staying the same ... [maybe] I’m still pumping meds into her body – for nothing.” She was unsure about a medication and clearly unsure about what to do next.

3.5. The need for pharmacist-led education

The pharmacist is the healthcare provider able to discuss, explain, and compare medicines fully. On asking a pharmacist about the difference between drug names, one patient stated that “when questioned, they were very quick to explain.”

4. Discussion

Understandably, a cancer diagnosis often causes the families to become flooded with emotion, forcing the family to adapt and cope with a completely different lifestyle after being blindsided by the unexpected. The results of this study suggest it would be a more effective use of time to provide an overview of the treatment and return after a day or so with more specific drug information when the notion of the cancer diagnosis has set in. The available literature supports this finding, with a report from Rodger et al. (2016) describing that upon diagnosis, parents received large amounts of information and immediately shut down or did not remember anything after that point, which made processing very difficult.¹³ In another study by Aburn and Gott (2014), they also described how some parents thought that taking in all the new information after their child’s cancer diagnosis was like learning a new language but found that the initial conversation with the physician was helpful in minimizing the families’ fears.¹⁴ The time for patients’ and families to settle post-diagnosis is not well documented so each case should be assessed on an individual basis.

Although these initial conversations are often held or directed primarily toward the parents of the diagnosed child, studies have shown that children would also like to be involved in the conversation to help settle their fears, uncertainties, and questions.^{15,16} While our previous study reported that children often feel excluded from medical discussions and also what they would like to learn, the interviews with children in this study substantiated these findings. The feedback from the children indicates that there is a need for the healthcare professionals to engage them more and ask what they would like to learn during medicine education sessions where possible. Including children from the initial diagnosis of their illness can help increase their overall knowledge and understanding of it, the medications, and why they are taking them, ultimately leading to increased adherence, health outcomes, and patient

satisfaction.^{10,17,18} Engaging children may be difficult at times as they may be distracted by their tablets or phones, or it may be difficult to assess their cognitive function. Still, when using a patient-centered approach, children are much more likely to engage and participate in the conversation.¹⁹

A new chronic illness diagnosis marks the start of a lifelong learning journey, learning how to manage the condition, the medications, and the associated psychosocial factors. As previously mentioned, patients and families are often overwhelmed at the time of initial diagnosis, but this is when the learning begins. The results of Rogers et al. (2016) support these balances of exchange revealed in this study, where they found that during the child’s inpatient stay, the conversations shifted from *telling* to *teaching* by the healthcare professionals as time went on.¹³ While the conversations during inpatient stays often become more of patient/family-healthcare professional collaborative conversations, participants in this study, particularly the families, noted that this typically reverts to *telling* rather than *teaching* upon discharge. At the IWK, medication calendars are usually distributed on the day of discharge, leaving limited time to provide one last education session to a family anxious to leave the hospital and get home. Although these calendars can help to ensure or improve adherence, they do not increase the patient’s understanding of what they are taking, just when to take it. Patients and families are often nervous or worried about going home for the first time and having to deal with everything on their own,¹³ so taking a more gradual approach to educating, starting from the initial diagnosis, may allow families to have time to sit with the new information, try to understand it, and ask any questions if needed. Continuous education may help to increase patient and family understanding, retention, readiness to go home, and overall satisfaction. This continuous education can be accomplished by the medicine educator repeatedly meeting with the child and family throughout the inpatient admission and periodically once they transition to outpatient. It is also important to provide medicine education not only when the child is sick but also at well visits to ensure that non-anxious moments of medicine teaching occur, likely increasing understanding and retention.

Throughout a patient’s journey with cancer, a lot of information will be passed from healthcare provider to patient and family, making it difficult to retain everything. At the IWK, upon initial diagnosis, patients are given a binder with written material and continuously updated handouts as treatment progresses. This study showed that those families who used and regularly updated the provided binders had a greater understanding of their child’s medications and fewer questions for the care team. Those who either lost the binder or elected not to use it admitted to having an insufficient understanding of the medications. Having material that patients and families can refer back to is often helpful because it usually contains information they did not know they wanted initially or were too afraid to ask about.²⁰ The materials surrounding topics, such as cancer or other complicated illnesses, often contain medical jargon and terms that the patients and their families may not understand, so it is more beneficial when given in plain language at an age-appropriate level, larger font sizes, and includes graphics.²⁰⁻²² In addition to supporting verbal information with written materials, it is also important that consistent communication strategies are employed to ensure all participating individuals understand and retain new information. Active communication intervention techniques encourage patient involvement and have been shown to significantly improve both knowledge and adherence to regimens.^{21,23}

Younger children are at an earlier stage of development, with lesser cognitive ability to understand in depth their medicines. It is therefore important to use appropriate language during medicine encounters with children.^{19,24} For example, a young child is not able to choose to take their cancer medication, but they may be enabled to choose a time of the day that works better for them. An older child may be given the responsibility of remembering when to take their medication and even self-administering the medicines. As the appropriate medicine education provider, the pharmacist should have the skills to assess the child’s level

of understanding and enable the child. For example, during the education session on the medication, the pharmacist should address the child directly in conjunction with the parent. The pharmacist should also ask the child if they have any questions regarding their medications. If the child is too young to understand, pictograms can be incorporated to help illustrate the medications in question. Information on the adverse effects of drugs can be discussed with the child directly in a language that is representative of the age of the child. How the drugs work may be a bit more challenging, but the results of our previous study did determine that children of various ages want to know more about how their medicines work, especially the teenage population.⁹ The pharmacist should review how the drug works with the child in a manner appropriate for the child's comprehension level. Teenagers are capable of abstract thought and would understand how the drug works inside the body, but some younger children may also be able to comprehend this. Learning always involves building on what the learner already knows. The pharmacist and other health care professionals should have an understanding of the differences between passing on information and supporting a patient's learning.

One significant finding from this study was the patient and family wishes for consistency. Different patients in this study noted other things relating to consistency, whether it be dealing with consistent healthcare providers with whom they feel the most comfortable or the consistency in the information given and how it is delivered. Participants also noted that the members of the team with whom they felt the most satisfied were those that they had the best rapport with, typically those they have had more frequent and pleasant conversations with. In addition, it was noted that the same is true for the person healthcare providers choose to speak to. These findings are consistent across various conditions, and patients tend to gravitate toward the health professionals they get along with best because they engage them, listen to them, and know their history.²⁵ Some healthcare professionals in this study acknowledged that positive relationships help increase medicine education outcomes. A study by Mohammadreza et al. (2011) found that diabetic patients with good rapport with an empathetic physician led to significantly better health outcomes and satisfaction.²⁶ While it may not always be possible to ensure that each patient gets their "favorite" person each time, all members of the team must try to establish a good relationship with the family and patient and provide consistent information to improve trust.

Standardized teaching approaches and consistent information were noted by patients to be lacking at times, leading to reduced satisfaction. Participants pointed out that some physicians would tell them not to use the internet for their personal research, while others would encourage it. With the availability of the internet and the amount of information out there, healthcare providers should discuss the benefits and possible damages of patients conducting their own research and provide them with appropriate websites with valid information. Other patients and families noted that certain healthcare providers would refer to medication by one name during some education sessions while another may use a different name. These discrepancies can increase the confusion and frustration of patients. Having a standardized teaching approach in place can help improve communication with the patient and the healthcare team. A performance improvement project by Blagojevic and Stephens (2008) showed that implementing standardized teaching programs could facilitate teaching and increase patients' knowledge and skills for condition management.²⁷ At the time of this study, all healthcare providers were involved in medicine education. Also, there were typical times during treatment when different healthcare professionals would meet with patients and families for information passing and education. Overall, the medicine education program, as it was during data collection, was partially effective. Patient and family care in pediatric oncology has been provided through an interdisciplinary team of oncologists, nurses, family care coordinators, pharmacists and more. Each member has their own expertise and plays a distinct role in the patient's care, which is crucial to the success of the treatment.

Through their schooling, pharmacists have developed in-depth knowledge about the medications and how they work, making them an essential part of the therapeutic management of disease and patient education. While other healthcare providers may be able to give an explanation of the medications the patients are on, pharmacists are specifically educated to teach patients about their medications, addressing the family's learning abilities and answering any drug-related questions they may have.

Adherence is the connection between treatment instructions and actual treatment. For most of these patients, adherence is "a matter of life and death." Some patients are fully adherent but know nothing about the medicines or their necessity. The major problems arise from those patients who do not understand their medicines and are not adherent. If adherence can be increased through a better understanding of the medicines, then it is the pharmacist who should provide this medicine education. The available literature supports pharmacist-patient education's effectiveness, utility, and benefits. In an inpatient setting, pharmacists have been shown to reduce the number of adverse drug reactions and length of stay in the hospital and, through patient education, improve adherence, health outcomes, and patient quality of life.^{18,28-32} Introducing pharmacist-led patient education from the initial diagnosis may help improve the patient and family's initial understanding of therapy options required to gain informed consent to start treatment and help prepare everyone for discharge. Also, this would help the patient/family member/caregiver recognize who the drug experts are and build this rapport early on in treatment. Implementing this education would allow for a slower and more gradual learning experience for the family to increase retention, understanding, and comfort while reducing anxiety immediately before discharge, setting the family and patient up to be more independent and self-managing.

The first element of medicine education is to decide on a variety of levels of knowledge and skills that patients and families should have. All learners are different, and there will be those who want to understand everything and others who do not want to understand anything more than what they absolutely need to know. Timing the education when the child and family member have low anxiety is best. More frequent and shorter sessions would allow to focus the education on less content so there is more time for discussing, repeating, reminding, and questioning the learners to improve their learning and retention. In addition, every subsequent session should start with a review of the previous session. Don't just read them what they "learned" last time; get them to access their memories and tell what was previously discussed. Accessing memories makes them easier to recall. Another important point is encouraging children and their families to ask questions, as this helps improve rapport and engagement in the learning process. Finally building rapport by way of frequent encounters between the pharmacist and the child results in the child connecting the pharmacist with their medications. Gaining the trust of a child goes a long way to improvements in learning.

There were several limitations associated with this study, one being time constraints. Due to a lack of time not all families, children, or healthcare professionals at the IWK were able to be interviewed. Interviewing families and children of varied ages may allow for more interaction and feedback from children and adolescents. Secondly, we also limited the inclusion of participants to those who are English-speaking. This may have reduced the feedback from those families and children coming from differing cultures/backgrounds. Thirdly, there was an uneven distribution of interviews from time of diagnosis which may have led to an incomplete assessment of learning needs over the course of treatment. And lastly, parents often answered questions on behalf of their children during interviews which resulted in a less authentic assessment of the children's learning needs.

5. Conclusion

A cancer diagnosis for a child is devastating. The timing of initial medication education is crucial to learning. This study determined that families need time to adjust to the new diagnosis before they can absorb any information about treatments. The families also noted that they need consistent information regarding their medications that includes the same names used and full discussions regarding how the medicines work to help improve their understanding of the numerous cancer drugs their children are required to take. It is the recommendation of the authors that medicine information should occur in depth sometime after the initial diagnosis disclosure and that a consistent member of the team review this information, in this case, the pharmacist or medication expert. This information should be given on a continuous basis, including visits when anxiety levels are low. Enabling children in their medicine education can be challenging for a busy clinic day. Still, it is important to engage the child at an age-appropriate level where possible in order to improve the uptake of medication adherence. The authors recommend that the medicine expert include the child in medicine learning to provide a lifelong appreciation for these life-saving medications.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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