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Understanding Effective Delivery of Patient and Family Education in Pediatric Oncology: A Systematic Review From the Children's Oncology Group CE

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Abstract

A diagnosis of childhood cancer is a life-changing event for the entire family. Parents must not only deal with the cancer diagnosis but also acquire new knowledge and skills to care safely for their child at home. Best practices for delivery of patient/family education after a new diagnosis of childhood cancer are currently unknown. The purpose of this systematic review was to evaluate the existing body of evidence to determine the current state of knowledge regarding the delivery of education to newly diagnosed pediatric oncology patients and families. Eighty-three articles regarding educational methods, content, influencing factors, and interventions for newly diagnosed pediatric patients with cancer or other chronic illnesses were systematically identified, summarized, and appraised according to the Grading of Recommendations Assessment, Development, and Evaluation criteria. Based on the evidence, 10 recommendations for practice were identified. These recommendations address delivery methods, content, influencing factors, and educational interventions for parents and siblings. Transferring these recommendations into practice may enhance the quality of education delivered by health care providers and received by patients and families following a new diagnosis of childhood cancer.

Keywords
education, pediatric oncology, family, new diagnosis, systematic review

A diagnosis of childhood cancer is a life-changing event for the entire family. The cancer diagnosis makes a significant impact on the patient and family, resulting in disruptions of roles and responsibilities, routines, relationships, and day-to-day functioning. These changes as well as financial and employment difficulties, marital stress, generalized uncertainty, lifelong side effects, and restrictions in daily life are some of the stressors that may affect affected families (Long & Marsland, 2011; Woodgate, 2006). Not only must families adjust to having a child with cancer, they must also acquire new knowledge and skills in order to care safely for their child with cancer at home. Additionally, families face an enormous learning curve, particularly within the first month of diagnosis.

Currently, there are no evidence-based recommendations available to guide the provision of patient/family education for newly diagnosed pediatric oncology patients and their families. Providers use their own discretion regarding educational content, delivery methods, and timing of education; educational practices that are most effective, appropriate, and useful for newly diagnosed patients and families are currently unknown. The purpose of this systematic review was to evaluate the existing body of evidence to determine the current state of knowledge regarding the delivery of education in

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Table 1. MeSH Terms used in Search Strategies.

Topic	MeSH Terms[a]	
Condition/disease	Neoplasms	Infant, newborn
	Diabetes mellitus, type 1	Brain injuries
	Diabetes mellitus	Head injuries, closed
	Anemia, sickle cell	Multiple trauma
	HIV infections	Spinal cord injuries
	HIV	Spinal injuries
	Epilepsy	Craniocerebral trauma
	Hemophilia A	Coma, post head injury
	Hemophilia B	Cranial nerve injuries
	Tracheostomy	Head injuries, penetrating
	Tracheotomy	Intracranial hemorrhage, traumatic
	Chronic disease	Skull fractures
	Premature birth	Injury severity score
	Infant, premature	Abbreviated Injury Scale
	Infant, low birth weight	
Child	Adolescent	
	Child	
	Infant	
Discharge	Patient discharge	
Education	Patient education as topic	
	Counseling	
	Teaching materials	
	Education (MeSH subheading)	

Abbreviation: MeSH, medical subject headings.

[a] Does not include keywords used in search strategy, only subject headings (MeSH).

newly diagnosed pediatric oncology patients and families. Evidence related to method, content, timing, influencing factors (eg, demographic), and current educational interventions was systematically identified, summarized, synthesized, and appraised, and final recommendations have been proposed.

Systematic Review Methods

The Children's Oncology Group (COG) Nursing Discipline leadership identified a systematic review leader and a mentor, who are doctorally prepared nurses with experience in mentoring systematic review groups. Through a competitive process within the COG Nursing Discipline membership, team members were selected and then given training on the evidence-based review process through a 2-day workshop.

The team developed 6 clinical questions to focus the systematic review. These clinical questions were created in the form of PICOT questions to ensure clear, concise, searchable questions. PICOT represents Patient, Intervention or Issue of Interest, Comparison, Outcome, and Time (Melnyk & Fineout-Overholt, 2015). The COG Nursing Discipline leadership team vetted the PICOT questions.

An experienced medical librarian (Leonardelli) helped to develop a search strategy for each PICOT question. The following online databases were searched using a combination of controlled vocabulary terms and keywords: MEDLINE (Ovid), CINAHL (EBSCO), and The Cochrane Library (Wiley). Table 1 contains the MeSH (Medical Subject Headings) terms used in the MEDLINE searches. Complete search strategies are available on request from the first author.

All database searches were limited to English language. Publication dates had no restrictions; however, conference abstracts, editorials, comments, and letters were excluded. Due to the limited results within pediatric oncology, the search was expanded to include other pediatric diseases or conditions that required the parent or patient to learn new information and/or skills. These diseases or conditions included diabetes, sickle-cell disease, human immunodeficiency virus, epilepsy, hemophilia, newly placed tracheostomy or central line, chronic diseases requiring hospitalization, traumatic brain injury, traumatic injury, and premature or newborn infants.

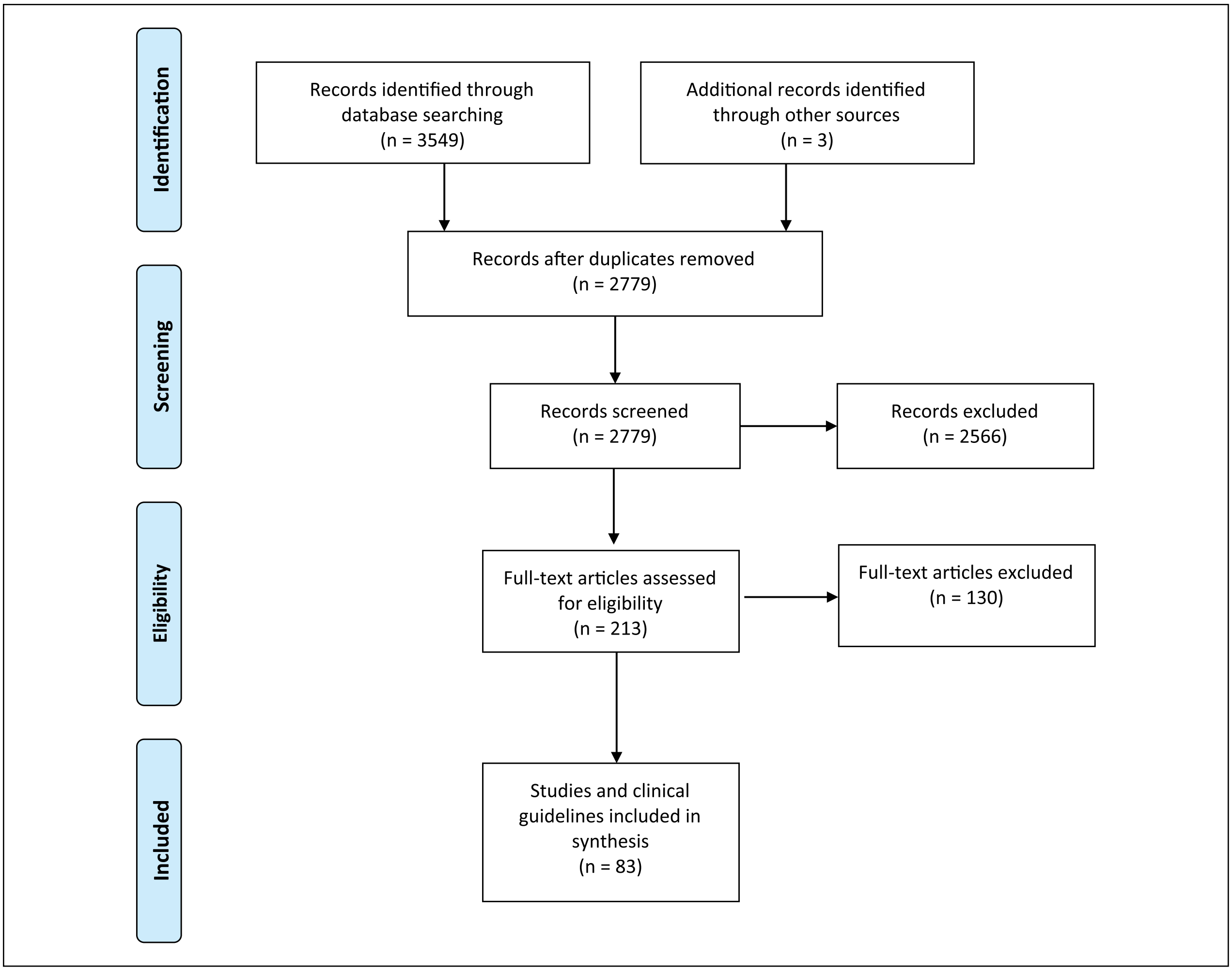

Figure 1. PRISMA diagram.
Abbreviation: PRISMA, preferred reporting items for systematic reviews and meta-analyses.

The search was last updated in August 2015. See Figure 1 for the PRISMA diagram (preferred reporting items for systematic reviews and meta-analyses; Liberati et al., 2009). Overall, database searches yielded 3,549 results, with 3 additional articles found after review of the reference lists of relevant articles. Removing duplicate articles revealed 2,779 unique records. The primary author reviewed the title and abstract of the unique records for empirical evidence specific to any of the PICOT questions. Unique records were excluded if they focused on education about cancer prevention or cancer risk, empirical evidence regarding adult cancers (eg, breast, ovarian, prostate), expert opinion, and education when the outcome was focused on the setting of care (ie, inpatient vs outpatient). Abstracts were also excluded. These criteria excluded 2,566 records, leaving 213 articles for the team to review. A full-text review resulted in the exclusion of an additional 130 articles due to the previously described criteria. Articles on informed consent were included in the initial review; however, full-text reviews resulted in the exclusion of these articles. In total, 83 articles are included in this review.

Using matrix tables (Garrard, 2014), individual team members summarized components of each article including purpose, design, variables, subjects, measurement tools, and findings. Team members also summarized issues related to the quality of the article according to the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) tool (Guyatt et al., 2011). These issues included methodological flaws, inconsistency, indirectness, effect size, and publication bias. Each member presented her matrix tables via conference calls. Group consensus was obtained regarding the relevancy of each article. Once the summary of articles was complete, the team synthesized the evidence and developed recommendation statements for practice. Using the GRADE

Table 2. Educational Methods Among Pediatric Patients Newly Diagnosed With Cancer and Their Family Members.

Method	Examples	Reference (First Author, Year)
Written	Educational binder Information sheets Booklets Literature from external agencies	Aburn, 2014; Burklow, 1988; Eden, 1994; Flury, 2011; Giacalone, 2005; Matutina, 2010
Verbal	Discussion with health care providers Informal discussion with other parents Patient-to-patient discussion	Aburn, 2014; Flury, 2011; Giacalone, 2005; Levenson, 1982
Internet	Search engines, such as Yahoo and Google American Cancer Society	Lewis, 2005; Aburn, 2014; Giacalone, 2005
Video	Taped diagnostic discussions	Eden, 1994

criteria, an overall rating for the quality of the body of evidence was determined, and recommendation statements (strong or weak) were identified (Andrews et al., 2013).

In addition to the database search, the team leader searched for clinical guidelines through the Agency for Healthcare Research and Quality clinical guideline website and websites of relevant professional organizations. Two team members independently evaluated 5 clinical guidelines related to the topic, using the Appraisal of Guidelines for Research and Evaluation II (AGREE II) tool (Cluzeau et al., 2003). During a group conference call, team members discussed the AGREE II scores and any concerns, then voted to determine if each clinical guideline was acceptable for use. By unanimous vote, all 5 clinical guidelines were included in the review.

Review of the Evidence

> **PICOT Question 1:** Among newly diagnosed pediatric oncology patients and their family members, what educational method(s) are most effective and preferred by patients and family members to address informational needs?

Educational delivery methods among patients newly diagnosed with cancer and their parents and siblings included written materials, verbal discussions, audio recordings, and the Internet (Table 2). Parents and siblings of children newly diagnosed with cancer reported written information as very helpful at the initial diagnosis and during discharge teaching (Aburn & Gott, 2014; Eden, Black, MacKinlay, & Emery, 1994; Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011; Matutina, 2010) because it provided information they were afraid to ask (Burklow et al., 1988). Parents of premature newborns and parents of children with diabetes, epilepsy, and other chronic illnesses supported these findings (Brett, Staniszewska, Newburn, Jones, & Taylor, 2011; Broedsgaard & Wagner, 2005; Hall-Patch et al., 2010; Mahat, Scoloveno, & Barnette Donnelly, 2007; Sawyer & Gazner, 2004; Woodward, Dawes, Dolan, & Wallymahmed, 2006). In general, parents of children with several different diagnoses (eg, cancer, diabetes, or newly placed tracheostomy) reported written information as helpful when it was simple, in plain language, brief, well organized, and in large font and included visuals such as pictures and graphics (Aburn & Gott, 2014; Kingston, Brodsky, Volk, & Stanievich, 1995; Nichol, McIntosh, Woo, & Ahmed, 2012).

Two studies reported that adolescents/young adults (AYAs) with cancer prefer a discussion with a health care provider (HCP) as their first choice for the delivery of education, while discussion with others and written materials were preferred as additional methods (Giacalone, Glandino, Spazzan, & Tirelli, 2005; Levenson, Pfefferbaum, Copeland, & Silberberg, 1982). Parents of children newly diagnosed with cancer also reported verbal discussions with HCPs as supportive, but these discussions were also described as overwhelming and exhausting (Flury et al., 2011). Parents of children with cancer or cystic fibrosis (CF) expressed a desire for an informal meeting with other parents but did not want this to occur until they had overcome the initial shock of the diagnosis (Aburn & Gott, 2014; Sawyer & Gazner, 2004).

An audio recording of the diagnostic talk was helpful to parents of children diagnosed with cancer and parents of premature newborns; this allowed them to replay and recall information that they initially could not absorb or understand (Brett et al., 2011; Eden et al., 1994). In addition, simple videos were an effective way to provide initial education to parents of children newly diagnosed with CF (Sawyer & Gazner, 2004).

Limited information is available on the use of the Internet for education, with mixed findings. One study reported 98% of family caregivers used the Internet for cancer related information when their child was initially diagnosed (Lewis, Gundwardena, & Saadawi, 2005), while another study found only 17% of parents of

Table 3. Teaching Strategies.

Strategy	Reference (First Author, Year)
Start with informal instruction, then move to more formal methods as the parents adjust to the cancer diagnosis	Aburn, 2011
Repeat information until the parents are able to comprehend the information	Eden, 1994
Encourage parents to watch as nurses ask other health care providers questions, to provide role-modeling of effective communication	Brett, 2011
Check that parents understand the information delivered by health care providers	Brett, 2011; Garwick, 1995
Establish a partnership and instill a feeling of being on a team	Aburn, 2011; Brett, 2011
Use the same nurse to provide information	Broedsgaard, 2005; Aburn, 2014

children newly diagnosed with cancer used the Internet (Aburn & Gott, 2014). Among AYAs with cancer, 23% used the Internet as a source of information (Giacalone et al., 2005). Parents of children with cancer and parents of premature newborns identified easy navigation, search capabilities, and individualized information for complex issues as important features in a website or Web-based program (Brett et al., 2011; Lewis et al., 2005). Patients reported limited use of the Internet as an educational tool, with only 23% of AYAs newly diagnosed with cancer reporting Internet usage in 1 study (Giacalone et al., 2005). Another study of AYAs recently diagnosed with HIV confirmed limited use, with only 28% using the Internet (Mayben & Giordano, 2007).

In addition to the method of delivery, the process of learning should be considered (Coates & Ryan, 1996). Teaching strategies for children newly diagnosed with cancer and their family members are listed in Table 3. Additional ways to enhance knowledge and reduce stress for parents of children with diabetes (Broedsgaard & Wagner, 2005; Sullivan-Bolyai, 2009; Sullivan-Bolyai, Bova, Lee, & Johnson, 2012) and parents of premature infants (Burnham, Feeley, & Sherrard, 2013) include experiential learning, such as acquiring specific skills and managing day-to-day care before hospital discharge. An additional recommendation among these parents included individualizing information (Brett et al., 2011; Burnham et al., 2013; Raffray, Semenic, Galeano, & Ochoa Marin, 2014; Sullivan-Bolyai, 2009).

- *There is a strong recommendation that written material, short verbal discussions, and audio recordings of the diagnostic discussion be used to provide education to pediatric patients newly diagnosed with cancer and to their parents and siblings.*

PICOT Question 2: What time frame after an initial pediatric oncology diagnosis is most effective and preferred by patients and family members for delivery of education?

It is important to recognize that when coping with stressful situations, some patients have a high internal locus of control and are information seekers, while other patients have a low internal locus of control and are information avoiders (Derdiarian, 1987). Most AYAs with cancer sought out maximum disease information at diagnosis as a way to gain control of the situation (Derdiarian, 1987); however, a survey of 563 professionals reported educating AYA patients later in treatment was more important than providing information at diagnosis (Bradlyn, Kato, Beale, & Cole, 2004).

Parents of children with cancer described an emotional strain immediately following the diagnosis that affected their ability to absorb information (Aburn & Gott, 2014). Parents of children with epilepsy and chronic diseases also expressed a sense of being overwhelmed immediately after the diagnosis and needed time to process the diagnosis (Hummelinck & Pollock, 2006; McNelis, Buelow, Myers, & Johnson, 2007). Parents of children with insulin-dependent diabetes recounted learning as mechanical at first in order to obtain survival skills, then eventually moved to learning more about caring for their child (Jönsson, Hallström, & Lundqvist, 2012; Sullivan-Bolyai et al., 2012; Sullivan-Bolyai, Rosenberg, & Bayard, 2006). This learning process allowed parents of children with diabetes to transition from a feeling of powerlessness to confidence (Wennick & Hallstrom, 2006).

While no article provided a specific time for the delivery of education to parents and children newly diagnosed with cancer, parents expected and preferred to receive information about their child's cancer diagnosis during the initial meeting with the oncologist. However, parents often became overwhelmed and needed time to process the information about their child's diagnosis before learning about essential care (Aburn & Gott, 2014).

- *There is a strong recommendation that parents of children with cancer need time to process the diagnosis before teaching about essential care can begin. No specific period is provided.*

Table 4. Educational Content for Newly Diagnosed Pediatric Oncology Patients and Their Parents.

Patients	
Cancer-Specific Topics	Psychosocial Topics
Knowing what will happen	How to interact and communicate with friends and family
Procedures	Getting back to school and making job/career plans
Prognosis	Learning how to adjust
Etiology	Relationships with and impact on family members
Treatment plan	
Side effects	
Everything (even the “hard stuff)	
For adolescents and young adults: sexuality and fertility information	
References (first author, year): Cavusoglu, 2000; Giacalone, 2005; Zebrack, 2013; Palmer, 2007	References (first author, year): Decker, 2004; Burklow, 1988; Derdiarian, 1987; Giacalone, 2005; Zebrack, 2013
Parents	
Cancer-Specific Topics	Psychosocial Topics
Diagnosis	Emotional impact on the child
Prognosis	Day-to-day management
Further testing	Making informed decisions
Treatment plan	Basic self-care
Understanding the disease	Coping with painful procedures
Side effects	Impact of cancer diagnosis on the family
Recognizing problems	
Medical dictionary	
Where to get answers for questions	
References (first author, year): Greenberg, 1984; Pyke-Grimm, 1999; Jackson, 2007; Flury, 2011; Sigurdardottir, 2014; Aburn, 2011; Hummelinck, 2006	References (first author, year): Pyke-Grimm, 1999; Flury, 2011; Sigurdardottir, 2014; Derdiarian, 1987; Aburn, 2011; Hummelinck, 2006

> **PICOT Question 3:** What location is most effective and preferred by patients and family members to deliver and receive education after the initial pediatric oncology diagnosis?

No evidence was identified to answer the question regarding the most effective and preferred location to deliver and receive education.

> **PICOT Question 4:** From a patient, family member, and HCP perspective, what educational content is important and preferred for newly diagnosed pediatric oncology patients and their family members?

Educational content considered important among patients with cancer ranged from cancer-specific to psychosocial topics (Table 4). Newly diagnosed children reported the most important information about their cancer diagnosis was knowing what was going to happen to them and understanding the etiology and prognosis (Freeman, O’Dell, & Meola, 2003). This is similar to information requested by children newly diagnosed with diabetes, who want information to understand their disease and treatment (Alderson, Sutcliffe, & Curtis, 2007; Schmidt, Bernaix, Chiappetta, Carroll, & Beland, 2012). Adolescents newly diagnosed with cancer ranked dealing with procedures as the most important topic followed by relationships with friends and getting back to school as the second and third important topics (Decker, Phillips, & Haase, 2004). Adolescents newly diagnosed with diabetes (Woodward et al., 2006) or epilepsy (Ridsdale, Morgan, & O’Connor, 1999) also reported the importance of knowing about social aspects of the disease and treatment. Several studies described that children and adolescents with cancer wanted to receive more information (Cavusoglu, 2000; Coates & Ryan, 1996; Freeman et al., 2003; Giacalone et al., 2005; Zebrack et al., 2013), but they were often unaware of what questions to ask (Palmer, Mitchell, Thompson, & Sexton, 2007; Sparapani, Jacob, & Nascimento, 2015).

While parents of children newly diagnosed with cancer likewise desired disease-specific as well as psychosocial information, several studies reported parents also want content related to practical or day-to-day management of their child's cancer (Aburn & Gott, 2011; Derdiarian, 1987; Flury et al., 2011; Hummelinck & Pollock, 2006; Sigurdardottir, Svavarsdottir, Rayens, & Gokun, 2014). A summary of content requested by parents is listed in Table 4. High-priority or essential information identified by parents at the time of their child's cancer diagnosis includes diagnosis, prognosis, further testing, and treatment plan (Greenberg et al., 1984; Jackson et al., 2007; Pyke-Grimm, Degner, Small, & Mueller, 1999); medium informational needs include understanding the disease, side effects, and the emotional impact on the child; and low informational needs included coping with painful procedures, and impact of the cancer diagnosis on the family (Pyke-Grimm et al., 1999). Information regarding the child's disease pathology, prognosis, treatments, medication side effects, and what to do in an emergency was requested by parents of children newly diagnosed with diabetes (Schreiner, 2013), epilepsy (McNelis et al., 2007; Reed, 2013), or CF (Sawyer & Gazner, 2004) and by parents of premature infants (Burnham et al., 2013).

Siblings of children newly diagnosed with cancer wanted to be at the hospital, talk to hospital staff and other patients, and be involved in the patient's care (Prchal & Landolt, 2012). Siblings worried about developing cancer like the ill child and wanted information on the diagnosis, etiology, and prognosis (Martinson, Gillis, Coughlin Colazzo, Freeman, & Bossert, 1990). When siblings were questioned about a new educational booklet, they described the book as useful, especially the content regarding curing cancer, learning about cancer, feelings related to cancer, and the glossary of terms (Burklow et al., 1988).

A Delphi survey of 199 pediatric oncology nurses reported treatment and disease information as important topics at time of diagnosis, and coping, symptom management, and treatment as important topics after the first week (Kelly & Porock, 2005). A survey of 563 multidisciplinary HCPs reported medical topics as more important than psychological topics to communicate to adolescent patients (Bradlyn et al., 2004). HCPs focused on survival outcomes and functional well-being while AYA patients wanted the focus on school, work, relationships, and fertility/sexual well-being (Thompson, Dyson, Holland, & Joubert, 2013). Pediatric oncologists' perceptions of educational content needs were similar to the parents' desired content, including diagnosis, disease process, prognosis, testing, treatment plan, and availability of physician (Greenberg et al., 1984). However, oncologists thought additional content should include dispelling the risk of contagion of the disease, parents not being responsible for diagnosis, normal parent reactions to diagnosis, what to tell the sick child, and who is the attending physician, while parents did not think those topics were important (Greenberg et al., 1984).

- *There is a weak recommendation that patients newly diagnosed with cancer and their family members receive medical information including information related to prognosis, etiology, procedures, treatment and side effects, and for adolescents and young adults, sexuality and fertility information.*
- *There is a weak recommendation that patients newly diagnosed with cancer and their family members receive psychosocial information including information related to learning how to adjust, how to interact and communicate with friends and family, relationships, impact on family members, getting back to school, and making job or career plans.*
- *There is a strong recommendation that health care providers use anticipatory educative content, as both the patient and family members are often unaware of what to ask.*

PICOT Question 5: Among newly diagnosed pediatric oncology patients and their family members, what are the demographic factors and/or clinical factors that influence the initial educational information delivered and received after the oncology diagnosis?

Only 2 demographic factors (age and educational level) were identified as influencing the initial education among pediatric oncology patients. Derdiarian (1987) reported that patients with higher education wanted additional written material about their cancer; however, the specific level of education was not stated. Age also influenced the amount of desired information at the initial diagnosis, with AYAs, aged 18 to 39 years, wanting more information than was received (Derdiarian, 1987; Zebrack et al., 2013). However, a study of 20 hemophilia patients found that developmental level, not age, should be factored into the education (Spitzer, 1992). Studies focused on pediatric patients with epilepsy (McNelis et al., 2007; Ridsdale et al., 1999) and diabetes (Schmidt et al., 2012) identified the following factors that influenced the children's ability to comprehend information: using words they could understand, receiving noncontradictory information, and feeling that HCPs had time to answer questions.

Factors influencing education delivered and received among parents of children with cancer or other diseases included delivery of information, emotions, language barriers, relationship with HCPs, the child's condition, and social issues. Table 5 lists the factors that negatively influenced education among parents. Issues with the

Table 5. Factors Negatively Influencing Education Among Parents.

Factor	References (First Author, Year)
Delivery of information	
Large amount of written and verbal information	Aburn, 2014; Farrell, 2013; Farrell, 2008; Flury, 2011; Hummelinck, 2006; Jackson, 2007; McKeller, 2002; Young, 2011
Use of medical terms and jargon	
Conflicting information from HCPs	
Child presence in educational session	
Emotions	
Fear, shock, grief, anxiety	Aburn, 2011; Aburn, 2014; Eden, 1994; Garwick, 1995; Hatton, 1996; Levi, 2000
Negative experiences with cancer	
Language barriers	
Lack of use of interpreters	Abbe, 2006; Miquel-Verges, 2011; Sullivan-Bolyai, 2009
Inability of the interpreter to accurately translate complex medical information	
Lack of understanding of cultural issues	
Relationship with HCPs	
Negative history with the child's doctor	Garwick, 1995; Levi, 2000; McKeller, 2002; Reed, 2013; Ridsdale, 1999
Overwhelmed with multiple HCPs teaching simultaneously	
HCP too busy to answer questions	
Inconsistent HCPs	
Not feeling like a partner in the team	
Child's condition and social issues	
Child's worsening medical condition	Aburn, 2011; Graf, 2008; Young, 2011
Lack of daycare or babysitting for siblings	
Lack of transportation to the hospital	
Information provided without child present, along with assurance that the child was comfortable and cared for	

Abbreviation: HCP, health care providers.

delivery of information, such as the amount of content presented, use of medical terminology, and inclusion of conflicting information, greatly influenced comprehension of educational material (Aburn & Gott, 2014; Farrell & Christopher, 2013; Flury et al., 2011; Hummelinck & Pollock, 2006; Jackson et al., 2007; McKeller, Pincombe, & Henderson, 2002). Emotional reactions and previous negative experiences with cancer made it difficult for parents to hear and comprehend information. Emotional reactions also influenced the ability to absorb information among parents of children with diabetes (Schmidt et al., 2012; Sullivan-Bolyai, Knafl, Deatrick, & Grey, 2003) or hemophilia (Furmedge, Lima, Monagle, Barnes, & Newall, 2013) and parents of premature infants (Sneath, 2009). Language barriers affected parents' ability to comprehend information. A descriptive study of 36 mothers found that interpreters for Latino parents of premature infants were needed 75% of the time but only used 67% of the time (Miquel-Verges, Donohue, & Boss, 2011). Despite the use of interpreters, language barriers may still be an issue due to the interpreters' inability to accurately translate complex medical information related to the care of pediatric patients with cancer (Abbe, Simon, Angiolillo, Ruccione, & Kodish, 2006) or failure to incorporate cultural issues for pediatric patients with cancer (Abbe et al., 2006) and diabetes (Sullivan-Bolyai, 2009).

The relationship with HCPs affected parents' ability to comprehend information, including past experiences with the child's doctor (Garwick, Patterson, Bennett, & Blum, 1995). Parents also felt overwhelmed when multiple HCPs simultaneously entered their child's room (Levi, Marsick, Drotar, & Kodish, 2000) or when the HCP was too busy to answer questions (McKeller et al., 2002; Ridsdale et al., 1999). Parents of children newly diagnosed with epilepsy found it beneficial when they had consistent HCPs and felt they were a partner in the team (Reed, 2013; Ridsdale et al., 1999). Parents missed planned educational sessions due to the child's medical condition, lack of day care or babysitting for siblings, and lack of transportation to the hospital (Graf, Montagnino, Hueckel, & McPherson, 2008). Parents of children with cancer wanted information about their child's diagnosis without the child being present (Young et al., 2011) but wanted assurance that the child was comfortable and cared for during educational sessions (Aburn & Gott, 2011).

Only 1 study evaluated factors affecting information received among siblings of patients with cancer. Thirty-two siblings related a lack of information about their sibling's diagnosis with cancer due to limited time with their parents or HCPs and a sense that little information was shared as a protective mechanism (Freeman et al., 2003).

- *There is a strong recommendation that educational and developmental level should be considered when delivering educational information to the pediatric oncology patient.*
- *There is a strong recommendation that educational information should be provided to parents by consistent health care providers, using vocabulary that the recipient understands, in a consistent manner, allowing time to answer questions.*
- *There is a strong recommendation that parents' emotional state, language barriers, cultural issues, and social issues (including transportation, sibling care, and the condition of the hospitalized child) be considered when providing education to parents.*

> **PICOT Question 6:** Among newly diagnosed pediatric oncology patients and their family members, what interventions have been developed to improve the comprehension of information related to the diagnosis, treatment, and care of the pediatric oncology patient?

Limited intervention studies were identified related to the education of patients newly diagnosed with cancer, their parents, and/or their siblings (Table 6). However, several intervention studies for patients and families of children with other diagnoses, including diabetes, premature or high-risk newborns, and recently placed tracheostomies, reported positive results. These interventions include Web-based programs, structured teaching tools, videos, and interactive education.

Two studies evaluated Web-based programs, including online education and support for patients newly diagnosed with cancer and their families. These patients and families primarily accessed the online discussion groups for support and found the support helpful (Ewing et al., 2009; Svavarsdottir & Sigurdardottir, 2006). Reasons for not accessing the site included being too overwhelmed with information and feeling too tired (Ewing et al., 2009).

Two studies evaluated structured teaching tools among parents or caregivers of children newly diagnosed with cancer (Matutina, 2010; Yilmaz & Ozsoy, 2010). Children recently diagnosed with cancer whose caregivers participated in a structured discharge program had fewer symptoms (eg, fever, nausea,vomiting, mucositis), central venous catheter problems, unplanned clinic visits, and unplanned admissions when compared to a routine care group (Yilmaz & Ozsoy, 2010). In addition, use of a novel teaching support (refrigerator magnet and wallet card) enhanced retention of important information among parents of children newly diagnosed with cancer (Matutina, 2010). Standardized teaching plans or checklists significantly improved knowledge among caregivers of hospitalized newborns (Blagojevic & Stephens, 2008) and children with recently placed tracheostomies (Hotaling, Zablocki, & Madgy, 1995). A discharge booklet and planning program was associated with increased knowledge and perception of readiness at discharge among parents of newborns (Cagan & Meier, 1983; McKeller et al., 2002; Shieh et al., 2010).

The use of videos as an educational strategy has not been evaluated among children with cancer and their families; however, studies among other pediatric populations found positive results. A virtual dialogue with a clinical neuropsychologist and a brain injury survivor was associated with a significant increase in family caregivers' knowledge and ability to communicate with HCPs when compared from before the virtual dialogue to after (Knapp, Gillespie, Malec, Zier, & Harless, 2013). Viewing informational videos was associated with a significant increase in knowledge and information application among parents of premature infants (Suk & Jiyoung, 2012), patients being screened for HIV (Bloch & Bloch, 2013; Calderon et al., 2009), or caregivers of children seen in the emergency department (Keane, Hammond, Keane, & Hewitt, 2005). A team of neonatal providers documented the process of developing an educational discharge brochure and DVD for parents of premature infants (Ronan et al., 2015). The providers identified important characteristics of an effective brochure, which included optimal organization, specificity of instructions, suitability for clients with a low reading level, and use of high-quality paper, while important qualities of the DVD include content parallel to the brochure and use of real-life video with parent involvement in a home setting (Ronan et al., 2015).

No studies assessed interactive education among children newly diagnosed with cancer; however, studies with other pediatric populations evaluated the use of skill demonstrations, parent mentors, and actively caring for the hospitalized child. Parents of children with a new tracheostomy (Tearl & Hertzog, 2007) or newly diagnosed with diabetes (Sullivan-Bolyai et al., 2012) who practiced skills on a manikin or simulator demonstrated more knowledge, problem-solving skills, and self-efficacy when compared to parents without the experiential opportunity. Survival skill training increased the comfort level of parents of newly diagnosed diabetic children (Schmidt et al., 2012). Parents who had the opportunity to care for their newborn or premature infant (Costello & Chapman, 1998) or for their infant with a congenital heart defect (Yang, Chen, Mao, Gau, & Wang, 2004) prior to discharge had more knowledge and confidence in caring for their baby after discharge. Parents of newly diagnosed children with diabetes favored the use of a parent mentor program on discharge (Sullivan-Bolyai, 2009; Sullivan-Bolyai et al., 2004).

Siblings of children with cancer benefitted from age-appropriate interactive education. Siblings who participated

Table 6. Interventions for Pediatric Patients With Cancer and/or Their Caregivers.

Intervention	Design/Variables	Sample	Findings	Reference (First Author, Year)
Web-based programs	Mixed-method study of Web-based resource, including information regarding emotions, issues related to childhood cancer, and electronic communication with research team	21 families including patients with newly diagnosed cancer, their caregivers, and their siblings	43% (N = 9) of families accessed the site, primarily on peer discussion groups Barriers to accessing the site included being too tired and too overwhelmed	Ewing, 2009
	Pretest/posttest design regarding educational website and online support	10 mothers and 9 fathers of children newly diagnosed with cancer	Well-being significantly improved after intervention No significant change in coping, hardiness, or adaptation 76% found website helpful	Svavarsdottir, 2006
Standardized teaching	Quasi-experimental design of discharge program (education, home visit, phone call) versus routine care	49 caregivers of children with cancer in Turkey	Control group had significantly more symptoms (fever, nausea, vomiting, mucositis, catheter problems), unplanned clinic visits, and unplanned admissions	Yilmaz, 2010
	Posttest design of teaching support materials (refrigerator magnet and wallet card)	3 parents of children newly diagnosed with cancer	Materials provided effective method for having phone numbers readily available and teaching parents when to call	Matutina, 2010

in the interactive sessions with a clinical psychologist or reflective journaling and personal diaries reported increased knowledge about their sibling's treatment and side effects, and decreased stress and anxiety (Nolbris & Ahlström, 2014; Prchal & Landolt, 2012). In addition, siblings of hospitalized children who participated in a program to explore medical equipment and receive information regarding illness, treatment, and daily routine of the hospitalized sibling had significantly less anxiety than siblings who did not participate in the program (Gursky, 2007).

Recommendations

From the body of evidence, 10 recommendation statements for children newly diagnosed with cancer and their family members were developed (see text). Current pediatric clinical guidelines include several of these practice recommendations, specifically the need for multiple methods for educational delivery (Cincinnati Children's Hospital, 2009, 2011, 2012), allowing time after the new diagnosis to process the information (Cincinnati Children's Hospital, 2013), and providing consistent information in understandable vocabulary with time for questions (Cincinnati Children's Hospital, 2011; Sheets et al., 2011). Finally, a clinical guideline focused on communication highlights the recommendation for a structured teaching tool for discharge information (Cincinnati Children's Hospital, 2011).

- *There is a strong recommendation that structured teaching tool(s) be used to guide the provision of general education and discharge instructions to parents of children newly diagnosed with cancer.*
- *There is a strong recommendation that siblings of children newly diagnosed with cancer should receive age appropriate, interactive education.*

Overall Quality of Evidence

Eighty-three articles were used as evidence to answer the PICOT questions. Evidence consisted of systematic reviews (N = 2), research studies (N = 80), and 1 unpublished dissertation. Research study designs included randomized control trials (RCTs), cross-sectional studies, pilot studies, pretest/posttest studies, postintervention studies, descriptive studies, retrospective chart reviews, case studies, qualitative studies, and mixed-methods studies.

Methodological flaws of the quantitative evidence included studies with small sample sizes and use of nonvalidated tools to measure outcomes. Several RCTs did not report their randomization method, and research assistants were not blinded to the treatment in 3 RCTs. Methodological flaws of several of the qualitative studies included lack of disclosure of rigor or interview questions. Two systematic reviews lacked details of methodology, including who performed the search, the search strategy, and the appraisal of evidence.

Two issues of indirectness were found in the evidence. The primary issue of indirectness was that most of the evidence was derived from samples consisting of mothers; fathers were not well represented in the evidence. The other issue of indirectness included 1 descriptive study that evaluated usage of the Internet only in a large metropolitan area, which may be inconsistent with other areas of the nation. No concerns were identified with inconsistency, imprecision, or publication bias. Overall rating of the quality of the body of evidence is low.

Conclusion/Discussion

Currently, no evidence-based recommendations exist in pediatric oncology to direct the consistent, effective delivery of cancer education to newly diagnosed patients and families. Identification of evidence-based practice recommendations can guide HCPs in providing consistent care to patients and families, increase awareness of best practices, and improve the quality of care and health outcomes (Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). This systematic review focused on identifying best practices for delivery of education to newly diagnosed pediatric oncology patients and their families. Ten recommendations were developed from the evidence, addressing 5 of the 6 PICOT questions. These recommendations focus on methods, timing, content, influencing factors, and effective interventions when educating children newly diagnosed with cancer and/or their family members. Transferring these recommendations into practice may enhance the quality of education delivered by HCPs, and received by patients and families.

Impeding development of further recommendations is the limited number and quality of published studies designed to evaluate education delivery methods for newly diagnosed children with cancer and their family members. Our team identified 83 research-based articles focused on the topic of education; however, only 33 of those articles related to a cancer diagnosis and the remaining 50 articles represented noncancer diseases and conditions. Only PICOT Question 4, focusing on educational content, contained more cancer-specific evidence than noncancer diseases and conditions. Furthermore, the majority of available evidence is from the parent's perspective, primarily the mother, with limited information from the fathers, patients (especially younger than adolescent age), siblings, and HCPs. Finally, the majority of evidence (53 articles) used in this literature review was more than 5 years old. The age of evidence should be considered when interpreting results such as method of delivery, which may not accurately reflect current options for educational delivery.

Additional studies are needed, including qualitative studies to further identify essential qualities of effective education among patients newly diagnosed with cancer and their family members, and quasi-experimental studies or RCTs to develop and evaluate educational interventions and identify factors that could influence comprehension of information (eg, age, literacy level, and language barriers). Dissemination of this evidence will allow for a better understanding and provide the knowledge needed to develop evidence-based guidelines for best practices in patient/family education of newly diagnosed pediatric oncology patients. Effective and consistent patient/family education can potentially improve understanding of the child's diagnosis, increase satisfaction and confidence with care, and improve the quality of life for children newly diagnosed with cancer and their family members.

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