

BARRIERS AND FACILITATORS TO IMPLEMENTING PSYCHOSOCIAL DISTRESS  
ASSESSMENTS IN THE PEDIATRIC ONCOLOGY SETTING

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## ABSTRACT

Mercedes Laurel Stanley: Barriers and Facilitators to Implementing Psychosocial Distress Assessments in the Pediatric Oncology Setting  
(Under the direction of Sheila Santacroce)

**Objective.** Our understanding of the barriers and facilitators to implementing psychosocial distress screening in pediatric oncology settings is limited. This capstone project explored perceptions of staff at a small pediatric oncology clinic about the barriers and facilitators to implementing psychosocial distress screening using the Psychosocial Assessment Tool (PAT) within their clinic.

**Methods.** Sixteen semi-structured interviews were conducted with clinic staff in various roles (licensed professional counselor n=1, child life specialists n=2, nurse practitioners n=2, physicians n=3, registered nurses n=7 and social worker n=1). Inductive thematic analysis was used to identify and interpret themes. Using the PDSA cycle (Institute of Healthcare Improvement, 2016), further strategizing regarding implementation will be conducted.

**Results:** Four main types of barriers to implementation emerged from the data: (1) patient family barriers including the ability to participate, reading level/language barrier, willingness to participate, fear of stigma, time; (2) staff barriers including time, lack of training/confidence, “buy-in,” ownership; (3) contextual factors including resources, clinic size, documentation and confidentiality; (4) PAT-related barriers related. Five main strategies to facilitate implementation also emerged from the data: (1) appeal to longstanding professional values; (2) formalize a process for universal screening; (3) use a team approach; (4) develop screening protocols and a resource guide that can inform referrals; (5) consult with other

programs. While the participants were not asked to directly provide strategies to facilitate implementation, these data were interrelated with their responses regarding barriers and facilitators and should be used to help build an implementation plan.

**Conclusions:** All barriers and facilitators identified in adult oncology literature were presented in this capstone project, while additional barriers and facilitators were identified in the pediatric oncology clinic that was the project site. While many of the concepts presented are generalizable, individual clinical programs should perform analysis of the specific family, staff and contextual barriers and facilitators to implementing psychosocial distress screening at their sites. In doing so, optimally effective and implementable approaches to psychosocial distress screening can be developed.

To the patient whose overwhelming distress changed how I view psychosocial care forever, this work is dedicated to you.

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## **LIST OF ABBREVIATIONS**

BLS	Basic Life Support
CLS	Child Life Specialist
EMR	Electronic Medical Record
LPCA	Licensed Professional Counselor Associate
MD	Medical Doctor
NP	Nurse Practitioner
PALS	Pediatric Advanced Life Support
PAT	Psychosocial Assessment Tool
PDSA	Plan-Do-Study-Act
RN	Registered Nurse
SW	Social Worker

## **CHAPTER 1: INTRODUCTION**

Each year in the United States, nearly 16,000 children and adolescents (ages 0-19 years, referred to hereafter as children) will be diagnosed with cancer (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). These children and their close family members experience psychosocial distress throughout the illness trajectory (Barrera, et al., 2014; Kazak, et al., 2011; Wiener, et al., 2006) and particularly during transitions such as diagnosis, beginning a new phase of therapy and treatment completion/transition to survivorship care. Relative to cancer, psychosocial distress is described as an unpleasant emotional experience that results in psychological pain due to the diagnosis of life-threatening illness. This psychological pain can affect how people feel, think and act. Responses to the diagnosis can range from normal feelings of sadness and fear to irrational fears, depression, panic, social isolation and anxiety at levels so severe that functioning is affected and professional intervention is required. These responses to psychological distress can lead to noncompliance with treatment regimens and thus poorer treatment outcomes (National Comprehensive Cancer Network, 2015).

Given the potential for psychosocial distress and its health consequences, the American Psychosocial Oncology Society, the Association of Oncology Social Work and the Oncology Nursing Society joint task force (Pirl, et al., 2014) introduced a recommendation that all cancer centers implement psychosocial distress screening programs. Additionally, psychosocial distress assessments have become a required quality of care standard for accredited cancer centers (Pirl, et al., 2014). This assessment necessitates using a standard tool to screen for psychosocial

distress, evaluate the results, and then refer as indicated for full assessment and intervention. The recommendation has six components:

1. A documented cancer committee meeting should be held during which psychosocial distress and screening is discussed. This committee is formed of individuals from the interprofessional team and does not include the patient. A representative from the institution's leadership must attend the meeting (eg: physician, nurse manager), along with a psychosocial representative, who may be an oncology social worker, clinical psychologist or other person trained in mental health (Pirl, et al., 2014).
2. The time of screening needs to be clear within the cancer center. The goal is to conduct initial screening of all patients and/or families within the first week of diagnosis. Recommendations regarding follow-up screening should be set by each cancer center.
3. The screening method should be established (e.g. patient-administered vs clinician administered or a dual basis) including who will perform or initiate the screening.
4. The screening tool that will be used must be determined.
5. How evaluation of the results and referrals as indicated will be managed must be established.
6. The screening methods, results, and the plan to address any distress and its source should be documented in the patient's medical record (Pirl, et al., 2015).

The Psychosocial Assessment Tool (PAT) (Kazak, et al., 2001) is one means of determining risk for psychosocial distress among children who have been diagnosed with cancer and their families. The PAT is a comprehensive assessment tool that is completed by the child's parent(s) or guardians, usually in about 5-10 minutes (Kazak, et al., 2001). The results are scored such that children and their families are assigned a risk category based on the

Psychosocial Preventive Health Model, and this risk category informs the level of psychosocial care offered to the child and family (Kazak, Scheider, Didonato, & Pai, 2015).

While no study has examined psychosocial screening rates in pediatric oncology settings, in adult settings these rates range from 47-73% (Deshields, Zebrack, & Kennedy, 2013; Zebrack, et. al., 2015). Assuming that the pediatric oncology screening rates are similar, these data suggest a pressing need to improve practice regarding universal cancer-related psychosocial distress screening including in the pediatric oncology setting.

### **Problem Statement**

Despite the recommendation from multiple oncology professional associations (Pirl, et al., 2014), the literature suggests that psychosocial distress screening has not been widely implemented. The problem of inconsistent screening for psychosocial distress in pediatric oncology populations has been evidenced in multiple studies (Barrera, et al., 2014; Kazak, et al., 2011; Wiener, et al., 2006). By implementing psychosocial distress screening, pediatric oncology providers can identify the most vulnerable families who need intensive psychosocial care to sustain their function and also more resilient families who require usual psychosocial care, which may be more intensive during transition periods such as the time around diagnosis (Kazak, et al., 2011; Barrera, et al., 2014). A necessary first step to using the PAT in a pediatric oncology setting to both comply with the recommendation concerning universal distress screening and inform psychosocial care level is to identify barriers and facilitators to implementation.

### **Purpose Statement**

The purpose of this project is to evaluate the barriers and facilitators to implementing the psychosocial distress screening recommendation in a small pediatric oncology clinic and how these barriers and facilitators can be addressed in the development of an implementation plan.

### **Clinical Practice Question**

What do direct care providers perceive as barriers and facilitators to implementing psychosocial distress screening in a small pediatric oncology clinical program?

## **CHAPTER 2: LITERATURE REVIEW**

### **Psychosocial Distress and the Psychosocial Assessment Tool**

Childhood cancer is a life-threatening chronic illness and the leading cause of death from disease in children. The American Cancer Society (2015) reports that 15,780 children ages 0-19 years are diagnosed with cancer each year. Of these children, 83% will survive their disease. This overall survival rate is attributable to treatment regimens that are typically multi-modal and aggressive. Parents of children with cancer experience multiple potential traumatic stressors throughout the illness trajectory. The child will often undergo chemotherapy, radiation, surgeries, and multiple procedures that require sedation (e.g. bone marrow aspirates, lumbar punctures, site biopsies); parents must authorize these procedures and are often present while they are performed. Witnessing or participating in these traumatic events can be a source of psychosocial distress for parents (Rosenberg, et al., 2013).

Psychosocial distress has been widely studied and identified within the realm of childhood cancer. The findings of a recent systematic review of 138 studies suggest that symptoms of psychosocial distress are common among parents of children diagnosed with cancer, with 25-30% of parents reporting distress even many years after the diagnosis and treatment completion (Kearney, Salley, & Muriel, 2015). Given the critical role that parents and other family caregivers play in their child's treatment for cancer, psychosocial screening throughout illness trajectory with referral for full evaluation and treatment as indicated is recommended (Kearney, Salley, & Muriel, 2015).



Another recent review of the literature found substantial high-quality evidence that supports implementation of the recommendation for regular systematic psychosocial screening in childhood cancer clinical settings (Kazak, et al., 2015). Implementing use of the Psychosocial Assessment Tool (Kazak, et al., 2001) for psychosocial distress around the time of the child's diagnosis could be a means to identify parent, patient, sibling and family-level risk factors, risk level and thus inform the level of psychosocial care to be provided.

### **Risk Factors for Psychosocial Distress**

Pre-existing parent, patient, sibling and family-level factors can heighten risk for psychosocial distress among families of children diagnosed with cancer.

**Parent risk factors.** Regardless of race or the child's cancer type, parents of children with cancer with low levels of social support, financial resources, and employment have an increased risk for cancer-related psychosocial distress (Karlson, et al., 2013). Other risk factors include single-parent households (Kazak, et al., 2001), lower level of parent education (Karlson, et al., 2013) and a history of mental illness or substance abuse in one or both of the parents (McCarthy, Ashley, Lee, & Anderson, 2012).

**Patient risk factors.** Children with cancer will undergo multiple therapies and distressing procedures during treatment. Children who enter their cancer experience with pre-existing emotional or behavioral concerns are at an increased risk for ongoing or worsening distresses. For example, a child with attention-deficit disorder or anxiety is more likely to have poor coping skills. Additionally, children who are less mature than their peers or have developmental delays will generally have ongoing issues or concerns (Kazak, et al., 2001).

**Sibling risk factors.** A recent systematic review performed by Yang, et al. (2016), found that siblings of children with cancer often reported feelings of anxiety, depression, loneliness,

and lack of attention from parents and other family members. Due to the already decreased levels of attention from parents, an increased number of siblings may increase risk for psychosocial distress (Yang, et al., 2016). Siblings with pre-existing mental or behavioral problems put the family at increased risk for psychosocial distress (Kazak, et al., 2001). Additionally, specific risk-factors for distress in siblings include the sibling being younger than the child with cancer, younger age in general, and the sibling being female (Buchbinder, et al., 2011).

**Family-level risk factors.** Usual life transitions such as marital separation or divorce (Karlson, et al., 2013) or family expansion through childbearing or adoption of a sibling (Kazak, et al., 2001) can be stressors that contribute to risk for psychosocial distress among families of children with cancer.

Every family enters the cancer diagnosis with unique concerns and pre-existing risk-factors. Understanding these risk-factors and their importance to psychosocial distress and adjustment allows direct care providers to focus on problem areas and provide support accordingly.

### **Barriers to Implementation of Psychosocial Distress Screening**

Despite existing recommendations and available tools, psychosocial distress screening is not routine practice. Patient and family member perceptions can be potential barriers to psychosocial screening and subsequent care. Many patients feel that they do not need such care or perceive stigmas in being screened or receiving care (Dilworth, Higgins, Parker, Kelly & Turner, 2014). Although the National Comprehensive Cancer Network (2015) intentionally uses the word “distress” to help reduce potential stigma, fear of stigma is still a possibility that could shape responses to screening items and affect the reliability of the results.

As with any new recommendation, contextual factors can act as perceived barriers and facilitators to implementation. While several studies have examined barriers and facilitators of psychosocial distress screening, no published study is specific to pediatric oncology. Among adult oncology clinicians, time to screen is the most reported barrier (Mitchell, 2013). Additionally, clinicians report lacking training and confidence to administer the screening tool and evaluate the results (Mitchell, 2013) and lack of available resources to address identified psychosocial distress (Mitchell, 2013; Dilworth, Higgins, Parker, Kelly & Turner, 2014). Similarly, oncology social workers report concerns about inadequate resources to address identified needs (Deshields, Zebrack, & Kennedy, 2013). Screening was less burdensome and more effective when the results linked to an algorithm for mandatory referral (Mitchell, 2013).

While the use of studies conducted in adult oncology settings can be informative, unique barriers and facilitators may exist in pediatric oncology. Currently, no known study has examined the barriers and facilitators that pediatric oncology clinicians, including nurses, perceive relative to their role in psychosocial distress screening as a component of comprehensive childhood cancer care. Further, the published adult oncology studies were conducted at comprehensive cancer centers. In general, community cancer centers have fewer available resources, which may heighten contextual barriers to implementation and referral. In contrast to clinicians at comprehensive centers, clinicians who practice in community-based adult or pediatric oncology programs may perceive different barriers and facilitators as they are in contact with fewer patients and fewer disciplines tend to be involved in these clinical programs. The goal of this project is to evaluate facilitators and barriers to implementing a psychosocial distress assessment program in a small community-based pediatric oncology clinic, and use these findings to provide recommendations for an implementation plan.

## CHAPTER 3: MODEL FOR IMPROVEMENT

The Model for Improvement (Associates in Process Improvement, 2016) shown in Figure 1 will guide this practice improvement project. This 2-part model describes a cyclic process to efficiently affect measurable improvement (Institute for Healthcare Improvement, 2016). In part

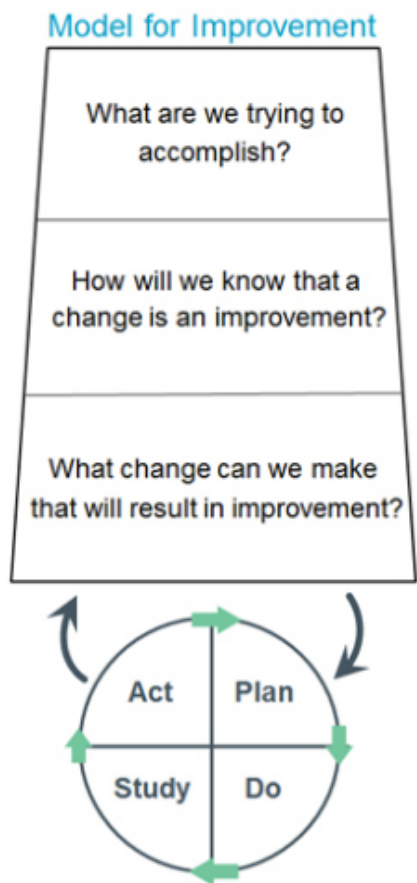


Figure 1: Model for Improvement (Institute for Improving Healthcare, 2016)

one, three questions are addressed: 1. What are we trying to accomplish? 2. How will we know the change is an improvement? 3. What change can we make that will result in improvement (Langley, et al., 2009)? These three questions can be asked in any order, as long as each of them is answered (Langley, et al., 2009).

To address question one, the specific aim for the improvement project is identified. This aim is often called a “charter” and provides a clear focus for the project. The aim is similar to a purpose statement and requires that the system being improved, the timeframe of the project, and the goals of the project be outlined in a clear, concise method (Langley, et al., 2009). The second question asks, “How will we know the change is an improvement?” To address this question, measurable meaningful outcomes are defined.

While large complex systems often require specific data be collected as evidence of change, smaller changes in a less complex system be assessed by observation (Langley, et al., 2009).

The third question asks, “What change can we make that will result in improvement?” To address this question, small yet important changes towards the ultimate aim are identified.

Once these three questions have been addressed, the second part of the model, the Plan-Do-Study-Act (PDSA) cycle, is activated. This cycle can quickly identify needs and apply ideas or processes for change. For large change, many small PDSA cycles are needed before effective implementation of the overall change can occur. In the planning (P) stage of the PDSA cycle, the team leader defines what needs to be done and how it should be accomplished, that is, a plan. In the do (D) stage of the PDSA cycle, this plan is put into effect and data is gathered based on the outcome measures identified. In the study (S) stage of the PDSA cycle, the data are analyzed and summarized. Finally, in the act (A) stage of the PDSA cycle, decisions are made about how to proceed to the next cycle based on the data collected from the current cycle (Institute of Healthcare Improvement, 2016). Each PDSA cycle is intended to be a small part of a larger improvement process, with multiple cycles within each improvement project. The cyclic nature of the process described by the model allows for quick and tangible results that can be modified or adopted before proceeding to the next cycle (Institute of Healthcare Improvement, 2016).

## CHAPTER 4: METHODS

### Part I: The Three Questions

The answers for these questions were provided by both the direct care providers in the community-based pediatric oncology clinic where the project took place and the literature. The following answers are in direct correlation with the purpose of this clinical project.

**Question 1. What are we trying to accomplish?** The charter for this project, that is, the answer to question one is to understand perceived barriers and facilitators to psychosocial distress screening as a first step in implementing the recommendation in the project site. Obtaining this information occurred over 1-2 months. The future goal is to have full implementation of the six-part recommendation within a year.

**Question 2. What change can we make that will result in improvement?** Using the knowledge that was gained from interviewing the clinic staff, an implementation plan and dissemination is being propelled forward. With careful preparation by using data given from the specific site, a summary of the results will be presented to the clinic staff to help aid in their implementation.

**Question 3. How will we know the change is an improvement?** At the present time, this clinic does not have any formal psychosocial assessment or program. By gaining data and producing an implementation plan, the clinic will be able to move forward in adhering to psychosocial recommendations and standards. This adherence would be considered a significant improvement for the clinic and its patients.

## **Part II: The Plan-Do-Study-Act Cycle**

The following PDSA cycle was the first of many cycles within this clinic prior to complete adherence to the psychosocial distress assessment recommendations. Using this framework, clear steps were outlined to begin the first cycle.

### **Plan**

**Design.** This project is the first cycle in a clinical practice improvement project. Prior to implementation of psychosocial distress screening in children with cancer and their families, qualitative data was obtained regarding perceived barriers and facilitators in this pediatric oncology environment. To obtain this data, participants from different disciplines of the healthcare team participated in semi-structured interviews with the project leader. Once these data were collected, barriers and facilitators were analyzed and used to help guide the planning for the implementation of the PAT.

**Setting.** The setting was a small privately funded community pediatric cancer program. The project site was St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital in Charlotte, North Carolina. The population within this center consists of patients from both urban and rural areas. Due to the St. Jude Research Hospital Affiliation, many of these patients are in clinical studies and all treatments are closely evaluated. The patient age range is 0-23 years; this clinic provides care for patients who are somewhat older than the typical pediatric and adolescent age range (0-19 years) if they have been diagnosed with a childhood cancer. The provider group consists of four pediatric hematology-oncologists and four nurse practitioners; they rotate between the outpatient and the inpatient setting. Twelve nurses, one social worker, one licensed professional counselor associate (LPCA), and three child life specialists also provide direct care at the project site.

**Subjects.** Participants were adults (aged 18 years or more) who are employees of the St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital in Charlotte, North Carolina. The sample was purposeful to fully capture the perspectives of the members of the various disciplines providing direct care (pediatric oncologists [3], nurse practitioners [2], the social worker [1], nurses [7], child life specialists [2], and the licensed professional counselor associate [1]). The goal was to achieve data saturation (i.e., themes were being repeated and no new themes emerged) and was proportionate to receive input from at least 50% of each specialty to help fully reflect the perspectives held by the direct care providers. The sample size was 16 direct care providers. Inclusion in the project improvement interview required: being part of the direct clinical care pediatric oncology healthcare team. Excluded from the study will be support staff who do not provide direct patient care.

**The Screening Tool.** Participants were asked their opinions about barriers and facilitators to implementing screening using the Psychosocial Assessment Tool 2.0 (PAT2.0), which was developed to determine risk for childhood cancer-related distress. The PAT2.0 was developed specifically to assess family members (e.g., parents, other informal caregivers, siblings, and the patient) in terms of factors that predict risk for psychosocial distress. These factors include parent, patient, sibling and family level-risk factors (Kazak, et al., 2001). The total PAT2.0 internal consistency has been shown to be acceptable (Cronbach’s  $\alpha=0.81$ ), as has test-retest reliability for fathers ( $r=0.87$ ) and for mothers ( $r=0.78$ ) (Pai, et al., 2008) Additionally, criterion-validity was high among both mothers and fathers, that is higher scores on the PAT2.0 were significantly correlated to later psychosocial distress (Pai, et al., 2008), which provides evidence for the predictive value of this tool.



Direct care providers were asked to consider the facilitators and barriers to distributing the tool to the family within the first week of the child's diagnosis and then collecting completed tools which will be scored by a trained staff member(s). Generally the tool is distributed, filled out, and collected the same day. Although the PAT is comprehensive, the parent, parents, or legal guardian of the child can respond to all of the 14 short sections in less than 10 minutes (Kazak, et al., 2001). The goal is that direct care providers will use this tool to screen risk for psychosocial distress in all families of children with a pending or new diagnosis.

The results are used to determine risk category (e.g., Universal, Targeted or Clinical) and subsequent level of care according to scoring criteria and the Pediatric Psychosocial Preventative Health Model (Kazak, Scheider, Didonato, & Pai, 2015). Families that fall into the Universal Risk category are considered well equipped to cope with their child's needs and their own fears and anxieties and require only usual general support. Families that fall into the Targeted Risk category are those that come into diagnosis with predisposed risk factors such as previous depression or financial hardships, or poor coping skills and are anticipated to need more than usual psychosocial support. Families in the Clinical Risk category presents with multiple defined risk factors, the most barriers to and/or the least functional coping skills. These families require referral for further assessment and intervention (Kazak, et al., 2001).

## **Do**

Project data collection was initiated after the project was reviewed and approved by the Institutional Review Board (IRB) at the University of North Carolina Chapel Hill and Novant Health. The project was also reviewed by the Nursing Research Council at Novant Health.

**Recruitment.** Project participants were informed about the project at a clinic staff meeting and also through fliers and email. The project and a brief informational segment

regarding the Psychosocial Assessment Tool and how it can be used was presented at the staff meeting. The short and long-term project goals were presented and staff was provided an email address where they could contact the project leader if they wanted to be involved in the study. Additionally, an email that included information about the study was sent to all direct care providers. Also, fliers with information about the study, including the contact information, was placed in popular areas around the clinic such as the bathroom, break room, and staff-only areas to inform staff who were not present at the meeting. See Appendix A for copies of these communications about the study.

**Consent.** Individuals who expressed interest in participating in the project were provided opportunities to ask their questions. Written informed consent to be audio-recorded was obtained prior to an individual's data being collected. Participants were counseled on the anonymity of their responses. To ensure confidentiality of their identity and their information, no personal identifying information was gathered in the audio-recording and all information about specific roles were removed from the data report. Each participant received a \$10 gift card to either Target or Panera Bread based on their preference after completing the interview.

**Data collection.** After written informed consent is obtained, each participant was asked to provide demographic data. Next, the participant was asked to engage in a pre-screening implementation interview; with the participant's permission the interview was audio-recorded and the interviewer made notes about the interview process after the interview had been completed. The interview was semi-structured in format, consisting of both closed and open-ended questions, and required between 8-60 minutes to complete, depending on the level of input the participant had. The demographic data form and the interview guide can be found in Appendix B. The interview questions were developed by the project leader based on the

literature regarding barriers to psychosocial distress screening in adult oncology settings (Absolom, et al., 2011; Dilworth, Higgins, Parker, Kelly & Turner, 2014; Oktay, Nedjat-Haiem, Davis & Kern, 2012). These questions addressed six themes:

- Knowledge of distress screening recommendation
- Thoughts on prevalence of psychosocial distress in children who have been diagnosed with cancer and their family members
- View of professional role of their discipline in psychosocial distress detection
- Knowledge of available screening tools and ideas on usability of these tools
- Knowledge of supportive services for the children diagnosed with cancer and their family members that are accessible in the community
- Barriers and facilitators to implementation of psychosocial distress screening and their ideas about how these barriers could be reduced or facilitators promoted.

## **Study**

**Data analysis plan.** Descriptive statistics were used to describe the participants as a group in terms of percentage of highest earned degree at the various levels (e.g., bachelor, master, doctoral degree) and median number of years of experience in their professional field and then specifically in pediatric oncology. The audio-recorded interviews were transcribed by the project leader. The project leader read the transcripts while also listening to the audio-recording as a means to familiarize with the data. Next, the project leader summarized each interview in one or two paragraphs. To allow for systematic data management, a data abstraction table was made to help sort the data into themes and identify linkages among the themes. Once initial themes had been identified, they were examined again for sub-themes (Powers, 2015). These themes were formatted into the data abstraction table that included results from each

participant to allow for comparisons, contrasts and linkages among themes and interviews, the goal being to address the barriers and build up the facilitators.

### **Act**

Following this analysis, summary information about the identified barriers and facilitators were provided to direct care providers at the project site. Additionally, links between the barriers and the strategies to address those barriers were presented, in an effort to provide efficient and useful data. Using this information, another PDSA cycle will begin as the clinic moves forward toward implementation.

## CHAPTER 5: RESULTS

### Sample

Sample characteristics are shown in Table 1. In total, sixteen out of the possible twenty-five (64%) participants who provide direct patient care volunteered to be interviewed. Each direct patient care group was represented in the sample. Participants had a mean 17.8 (11.3, 1.5-40) years of professional experience. The majority of the sample (68%) had spent most of their professional experience working with children with cancer, the mean being 13.1 (10.1, 0.41-33) years in pediatric oncology. Their level of education ranged from a diploma in nursing to a doctorate with 50% having a graduate degree; one participant had both clinical and research training at the doctoral level.

**Table 1.** Sample Characteristics (N=16)

<b>Professional Role</b>	<b>Participants of this type (n)</b>	<b>Percent of those eligible (%)</b>
<b>Licensed Professional Counselor Associate</b>	1	100%
<b>Child Life Specialist</b>	2	66%
<b>Registered Nurse</b>	7	58%
<b>Nurse Practitioner</b>	2	50%
<b>Physician</b>	3	75%
<b>Social Worker</b>	1	100%

## **Barriers to Psychological Screening as Identified by the Participants**

Barriers were conceptualized as any actual or perceived process that could impede implementation of the PAT and the six requirements outlined in the psychosocial distress screening recommendation. Barriers were comprised of patient/family barriers staff barriers, contextual factors, and barriers specific to the PAT.

**Patient/family barriers.** Multiple themes were identified in relation to barriers that related specifically to patient and family factors that made psychosocial screening difficult. These themes included: patient/family ability to participate, reading level and language barriers, patient/family willingness to participate, fear of stigma, and patient/family time.

***Patient/family ability to participate.*** For a screening tool to be successful, it is necessary that the patient or the caregivers are able to think clearly and fully participate. The recommendation is that screening be performed within the first or second week after a new cancer diagnosis (Pirl, et al., 2014). Staff commented that the medical diagnosis and typical psychological response to the diagnosis could impede on the family's ability to think as clearly as required for full participation in psychosocial screening. One of the child life specialists noted this barrier,

... for a new diagnosis that first week, ... you have all of this new information...still trying to figure out ... the treatment plan ... getting all of these resources/support thrown at you ... families may not be 100% committed to filling out the assessment, or it may just be too overwhelming at that point and you don't get a true full assessment ...

***Reading level and language barriers.*** The large urban area of Charlotte, North Carolina is populated by people from different backgrounds, both in terms of reading level and in primary language. Multiple staff members were concerned that some families would not be able to fully participate due to these barriers,

... how do you handle individuals and their education level? And I know there's a lot of families ... that wouldn't be able to do a very effective job because I don't think they would understand it too well. Is this going to be translated into all the different languages of the families that we treat?"

Additionally, one of the physicians commented,

A lot of our ... parents are very proud and don't want to share that they don't read well. And this is a very comprehensive form...it would be kind of overwhelming. So, it might be helpful for us to have a social worker or some other person help with the tool and answering these questions to get them done.

***Patient/family willingness to participate.*** Much of the staff was concerned about patients' and parents' willingness to participate in the psychosocial screening.

More the willingness of the families...seeing it's (psychosocial care) a good thing and getting them to participate in it. I feel like that's going to be the most challenging, because I mean we struggle to get some of our patients here just to get (medical) treatment.

Due to this potential lack of willingness, staff felt that patients and families may not provide accurate responses on the PAT.

... whether patients are completely honest or not...you've just done the tool, it ... starts the conversation, but ... be sensitive that there may be things that people don't disclose ... that show up later.

***Fear of stigma.*** Two staff members - a nurse practitioner and a physician, discussed fear of stigma related to psychosocial issues.

NP: ...getting labeled that they need psychosocial help might be something too.

MD: ... there is a stigma associated with seeking behavioral health services or mental health services so people ... may not ... feel at ease kind of talking about things, which they may not realize directly impact the patient and the family.

***Patient/family time.*** Time was one of the most reported barriers to screening, with 8 references to patient/family time. Participant comments on the topic of patient and family time were brief. Despite the overall assumption that starting a psychosocial program that included

psychosocial screening would be well accepted, patient and family time had not been previously considered.

MD: A lot of our parents ...want to get out, they've got to go to work ... (the PAT) is 15 more minutes or so.

LPCA: ...if they have other social stressors...finances...other kids they are trying to keep on a regular schedule in school, ... trying to keep their jobs, they want to be able to use their time for other things.

While patient and family time and ability to participate due to ability to focus during difficult times, reading level and/or level of education, and competing demands on their time are barriers to any type of medical care, themes related to fear of stigma and willingness to participate are identified specifically toward implementing a psychosocial distress screening program that uses the PAT. Overall, these themes were reported by each role group and have a large impact on how the staff perceives the ease of implementation with patients and families.

**Staff barriers.** Staff members have a large responsibility in the implementation of the PAT and the ongoing assessment and follow-up that it requires. They identified multiple barriers that include: staff time, lack of training/confidence, and evaluating results, staff “buy-in,” and ownership.

**Staff time.** In total, there were 17 comments made by nine different staff members regarding staff time. While the PAT may only take 10-15 minutes to complete by the family, additional time is needed to score the tool and determine appropriate resources/needs. Fitting this in with the work that the patient and family must do during a clinical visit or hospitalization and the workflow of the staff is a substantial barrier in settings where much of the work is time-sensitive. Except for the child life specialists, every staff subgroup identified time as a barrier to psychosocial screening and psychosocial committee meetings, particularly the staff nurses. One nurse stated,



Barriers are finding the time ... we basically put our foot in the door and we are off and running ... until the end of the day.

Another nurse stated,

We're struggling now with our work flow ... rooming the patient, med reconciliation, ... assessments of their needs, accessing their central line, drawing labs, education for the parents ... one nurse has so much and you only have 30 minutes and sometimes they'll double book ...our schedule is so jammed pack.

Additionally staff felt that although psychosocial screening is important, approaching it appropriately takes time and thus is often left out.

...one of the more important parts ... also take the longest to get out of somebody ...you only have so much time. So time is a big factor, yeah.

On the other hand, participants stated that time cannot be an excuse. For example, one nurse specified,

...the first pushback you are going to get is, "Ahhh, I don't have time..., when am I going to do that?" Well, ... we need to figure it out; we need to make time.

***Lack of training/confidence.*** Multiple staff members representing a variety of disciplines noted that they felt uncomfortable with some of the questions on the PAT, and therefore they did not have the training and confidence needed to perform the screen and evaluate the results. This discomfort caused staff to exhibit "avoidance tendencies" related to asking difficult or uncomfortable questions. Additionally, staff did not want their lack of training to burden patients and families. One of the physicians summarized this, saying,

... staff might not be trained in this area, and feel very uncomfortable approaching families at... acute points of distress... in the first couple of weeks of their diagnosis ... are you putting another undue burden on the family?

***Staff "buy-in."*** Despite the screening recommendations and overall agreement that some degree of distress is typical during the cancer experience, especially around the time of

diagnosis, staff noted multiple times that implementing psychosocial screening assessments were not necessarily widely accepted as being required within the clinic.

You've got a lot of old ways of doing things and a lot of protectiveness and a lot of 'we don't ask those questions'...how do you battle that?

...everybody has to be on the same page...some of those questions to me, if they are identified as a stressor ...as in "cancer is a death sentence" ...who is going to address those? ... a big change and ...buy-in from everybody. And I mean everybody.

Staff, particularly registered nurses, felt that the assessment could feel like an additional, and potentially unnecessary, "box to check off." Many nurses felt that psychosocial care is performed well within the clinic.

...our group does a great unofficial way of documenting and managing... (patient and family) stress on a relationship level and trying to pick out things that are worrisome and getting resources... because of relationship building and assessments.

...we throw so much paper at people when they walk through the door ... they sign and move on... And we have so much paper thrown (at us)... I'd hate for it to become... another "Let me get this done, so I can move on."

Social work added,

...is this going to be something that's not as important as making sure that a family has a place to live, or that ...I go to an IEP meeting... when does (psychosocial screening) become a chore or a priority?

Of note, one staff member stated that the fact that the screening is a recommendation and not a requirement might influence the resistance to change.

... requirement is, "Well, gosh, I don't have a choice" versus a recommendation ... (I'm) not changing ... this is the way I've done it and this is the way I work."

**Ownership.** Excluding the counselor, one or more representative of each role group identified ownership (or lack thereof) of psychosocial screening as one of the largest barriers to implementation. For example,

NP: ...who is going to own this? ... our social worker ... is very strapped for time.

MD: I've been at places where people are designated, and paid for (doing screening)

CLS: Someone would have to take ownership... not sure whose role that would be.

RN: ...this would have to be set on somebody ... [besides nursing]. Is that where we are going ... this is something all in itself.

SW: ... it may be that we have another counseling position ... if we decide to implement this, maybe that's part of their role.

Overall, each staff barrier related to the inherent fear or concerns that healthcare workers face on a regular basis - that they may not be able to do well what they need to do to meet the needs of their patients.

**Contextual factors.** Although contextual factors influence practice improvements in any setting, these factors can be particularly influential in the development of something entirely new to the context. The main contextual factors identified within the clinic were available resources, clinical program size, and documentation and confidentiality of sensitive information derived from the PAT.

*Available resources.* Although the general topic of resources were mentioned 16 different times by multiple participants, their ideas about resources varied widely. Some alluded that the one social worker could meet all of the needs, while others felt that lack of resources and reimbursement for psychosocial aspects of care were major barriers to implementation of the screening recommendation. While the staff spoke highly of her, the social worker felt that the patient load was too high for her to meet all of the different and unique needs that could be identified on the PAT. When asked if help could be found within the existing staff, the social worker noted that,

I don't know who ... nursing is managing a larger volume of patients every day . . . the human resource part is going to be our biggest limitation...you have to grow to ... overflowing and then you can hire some new people.

Reimbursement for psychosocial care was a common concern. One physician stated,

... psychosocial issues are not often reimbursed, we ... put them to the backburner... we're trying to be more efficient ... do more with less, and less people ... psychosocial issues is something that's suffered.

Despite the concern that resources may not be readily available, staff noted that the need for additional resources would not be fully recognized until screening was in place.

...you're not going to have the resource if you don't even know there's a problem... the only way... to make that resource available is by identifying that need...

***Clinical program size.*** The clinical program has a relatively small population of patients in the treatment phase (roughly 30 patients) of the illness trajectory, which was reported as a barrier to implementation of psychosocial screening due to insufficient supportive infrastructure. Many pediatric oncology programs are larger and/or part of academic health care systems and thus have more human capital and other resources to draw on to accelerate innovations in quality cancer care.

...a lot of pediatric hematology/oncology programs are academic based...a whole different structure for behavioral health support ...staff in behavioral health of different levels ...psychology and things like that.

...maybe it's the infrastructure ...more of the team, the layers of the team, and bridging that gap between behavioral health and ...our patients.

...I am in a little bit of a silo here....to not have anybody here with any real expertise in this makes it hard.

Additionally, due to the small population, staff has close relationships with the patients and their families. These close relationships engender protective instincts, which can impede psychosocial screening. For example,

...this clinic is so small ...people feel so protective of the families.

I wonder if the (another discipline) ... want to protect the patients from what they think may make them feel bad.

Lastly, given the small size of the clinical program, inadequate physical space was also as a barrier to screening. Specifically, if attaining additional staff to do screening is possible, a barrier to screening implementation becomes the limited amount of private spaces where patients and families could be screened in private outside of the exam room and not disrupt patient flow.

***Documentation and confidentiality.*** Due to the sensitive nature of some PAT items, documentation in the medical record and confidentially were concerns for nurses, social workers, and physicians. Interviewees expressed fears that the information could be accessible to others via the electronic medical record (EMR), and that there could be repercussions for the family.

For example,

...some things are a little more private...there are some things on (the PAT) that, you know, don't necessarily need to be known by everyone, all the time.

...confidentiality may be another aspect to a barrier or something that just needs to be thought out, in terms of how to make this work.

Staff also noted that, while the screening results should be noted in the patient's chart, some responses would not warrant immediate intervention but in retrospect could foreshadow future incidents. Concern was raised about the implications for staff in the event of an audit and questions about how these issues were addressed.

In summary, the contextual barriers identified were interrelated, for example, the small size of the clinical program and protective factor influence the concerns about confidentiality, and the lack of resources including human resources and physical space. Additionally, the lack of resources influences the concern that the potential needs identified on the PAT may not be adequately addressed.

**Barriers related to the screening tool.** The PAT was the suggested tool for this psychosocial screening in project site. Staff felt that the PAT did not provide space for explanation within the form, and that it may be too long for screening (as compared to comprehensive psychosocial assessment). For example,

...some things require some clarification...sadness meaning depressed or does keep to him or herself mean ...that temperament? ...a victim of ...abuse, or violence...is that...currently being investigated? ...this form does not allow you the tools to write down some of those other things.

On the other hand, another interviewee said, "...3 pages ...it needs to be as easy as possible."

Overall, barriers identified were related to four broad themes, including barriers specific to the patient and family, barriers specific to the staff, barriers specific to contextual factors, and barriers related to the screening tool itself.

### **Strategies for Addressing Potential Barriers**

Facilitators, or strategies, for addressing potential barriers were conceptualized as processes identified by the interviewees to improve the chances of successful implementation of psychosocial screening. These strategies included using universal screening and formalizing the screening process, appealing to longstanding values held by healthcare providers, using a team approach, building protocols for substantial findings on the PAT, and consulting with programs that already use the PAT.

**Universal screening/formalizing the screening process.** No other individual category of barriers or strategies had more comments than the need for universal screening and a formalized screening processes. In all, there were 43 comments on this set of strategies, with every discipline commenting. Staff felt strongly that if the screening implementation were going to be effective, it would have to include a formal tool given to every patient.

NP: ...if it was just part of the process ... it would be easier...an expected thing for families instead of ...an option.

MD: Psychosocial evaluation should be a component of what we do ... how we were doing it, it was like it was an addendum.

RN: ... it needs to be said up front ... this is just part of our program and it's expected. We're not saying you're crazy, we're not saying you need help ... we're saying that everybody is stressed and we recognize that ... it should be presented as, "This is your new medicine, this is your testing, this is what your life is going to look like, and this is to help you."

Most staff agreed that this process should begin with the patients who are newly diagnosed.

LPCA: ...best to start with new patients, so people who are coming immediately at that point, verses introducing it now.

RN: ... starting with new diagnosis ... to get the ball rolling rather than someone that's been getting treatment for a year and a half ... all of the sudden you have this new program, and "I'm not really interested in doing that."

Rational behind the universal screening included preventing "misses," controlling for subjective judgments about whom to screen and when to screen them, and "normalizing" the process for patients and their families, and possibly staff too.

NP: ...we can be misled by families...families may seem like they have it together, but ...they really may be in a lot of distress...other families, they may seem ...scattered and apart, but they're okay, that's how they handle things. We make judgments (based on) the perception of that provider or nurse that day...a formal tool may make that a more objective.

MD: ...I've certainly met families where I've thought, "Oh this family is so intact, so together" ... two months into their treatment, things just blow up. I look back and thought, "Oh, I thought I had asked this that and the other" Any screening, review of systems, physical exam, if you do it on every patient, you're not likely to miss an issue that could have been addressed early.

SW: ... the formal assessment would make sure that we don't miss anything ... some questions on there that can be uncomfortable ... but that doesn't mean that they're not important...it makes it easier to ask those questions as part of a formal assessment ... it could potentially help us recognize things that we might be missing or that families don't necessarily want to share up front.

**Appeal to longstanding professional values.** When asked, “How do you feel that your professional role plays a part in distress assessments,” participants spoke to having been trained to provide “holistic care” for patients and their families. Nurses, physicians and social workers noted that psychosocial care should be routine and required.

When I was trained...that was part of the whole person, and getting them prepared for consent, to find out what were the social and psychosocial barriers.

...I appreciate you taking this on ...as a nurse realizing that it’s part of their treatment ... part of our care.

... it needs to be said upfront ...“This is what you’re going to get ... we want to be sure that you’re holistically taken care of.”

Whether or not we provide this service or not, we need to ... realize that, parents staying together ... are part of the success of this treatment and the wellbeing of this child. To say, “Well we are only treating the child,” is not really treating the child ... we need to remember that ...

These responses focused on the inherent need to provide holistic care to every patient, despite the potential barriers. By reflecting on the missing aspects of the care provided at this clinic, staff was able to identify with longstanding values they received in their various educations.

**Using a team approach.** Staff was asked about their role in performing distress screening assessments, and who they felt was best suited to perform these assessments. Overall, participants agreed that social work was best prepared to perform the screening, and others could fill in the gaps. The social worker also felt that her role best accommodated screening. Nurses and nurse practitioners said they could perform initial assessments, but may not be best suited. Their larger concern was scoring the results and providing referral for follow-up as indicated based on the score. Physicians felt that their role should be to assure that the screening process is



completed, but not to screen. Child life viewed their role as being able to provide support as indicated based on the screening results.

SW: ...it would probably be most appropriate for me to complete the assessment...I don't think it would be so much of an issue doing it initially.

RN: ...nurses can play a role in administering a tool ...not sure we're the best ones to do that, but we definitely could be. For sure, nursing plays a role in identifying patients who need further assessment.

NP: ... (the NPs) do patient education at the very beginning with the handbook...medication information...we could give them the assessment tool as part of that process.

MD: To facilitate, to make sure that it's done...I can help with that, but I'm not a psychosocial professional, although sometimes I feel like it.

CLS: ...child life would have a part in following up and providing support, ...supportive listening and therapeutic conversation.

Most of the disciplines agreed that a team approach was key. Specifically, participants acknowledged that patients and families connect with different individuals and may feel more comfortable with those staff members distributing the PAT to them. This means that everyone would be involved in ongoing assessments and communication with patients and families about the requirement. Furthermore, one nurse explained that the more inclusive and team-oriented the approach, the greater chance for success in implementing the screening recommendation.

MD: I'm old school, I believe that the physician...nursing...the whole team, should assess...families disclose just a little bit different to each person.

RN: ...organizing a team is paramount. It's not a one-man show. You have to have several members of your team on board with this.

**Protocols.** One of the most addressed concerns was what to do with screening results and how to proceed after the initial assessment. This strategy involved developing a protocol to guide the entire screening process. Protocol elements that would need to be addressed and prior to implementation included timing of screening, how screening would be performed, whether

scoring would be done in real time or after the form is completed by caregivers, an organized approach to referrals, reassessment guidelines, and a resource book.

***Timing of screening.*** Opinions about the timing of the screening varied among staff.

Although the recommendation suggests screening within 1-2 weeks of diagnosis, opinions about this varied, mostly due to the fear that early screening would overwhelm families in crisis.

MD: (within the first week) they're captured ... in the hospital usually for a week to two weeks ... after about the first week ... they're bored, if things are going well. So that would be a good time for them to ... get into this, or reject it outright, but at least they would be in a position to do it I think.

RN: ... it would have to be done at every time to capture what the heck is going on, because stuff changes all the time ... might be good for a snapshot ... you're not going to capture what happens in the meantime.

A strategy suggested by the social worker was to ask previous families to look over the screening tool and give feedback on timing could be useful prior to implementation.

SW: How would you feel if I asked you this question at week number two ... might be valuable feedback ... they might say, "Oh my gosh this is overwhelming, I don't know what I would do if you asked me ... these are things that I didn't think about..."

***Screening modality.*** Another part of the protocol that would need to be addressed prior to implementation involved thinking about how initial screening would be performed. The tool could be distributed to the patient and family by a staff member, and then scored and addressed with the family at another time. Alternatively, a staff member could conduct the assessment. The staff member would use the tool to guide their assessment and record the responses to the PAT items. Modality could be patient dependent and follow algorithms agreed upon prior to implementation.

SW: ...if you give this to a family to fill out...and they give it back to you...it's an opportunity to say, "Thank you for filling this out. What I'd like to do next week is go over these things that you answered yes to, and figure out ...things that

we can help with...things that the school can help with...things that were so far in the past, they've resolved?" ...we need to figure (that) out...

***Organized approach to referrals.*** Due to the small size of the clinic and limited resources, psychosocial support will not always be available within the clinic, which was anxiety producing for staff. One of the strategies identified to facilitate implementation included establishing referrals based on screening results.

MD: ...we need to know...who's that "go-to" person for a family that needs marital counseling...to deal with addiction issues...we fly by the seat of our pants. But there are resources out there...having an organized mindset about that is not out of reach.

SW: ...I (will) need some back up support to deal with the more serious issues.... depression or suicidal thoughts...I'm not saying that we're going to have lots of those, but we need to make sure that we have tools and resources in place...

***Reassessment guidelines.*** While follow-up on initial assessments will depend on individual scores and responses, reassessments are not as straightforward. Furthermore, the literature does not give recommendations about reassessment. Staff acknowledged that the protocol should include guidance about reassessments. Additionally, one of the nurses noted that asking for information without a plan for ongoing reassessment is irresponsible. After determining how frequently psychosocial needs should be reassessed, building reminders into the EMR might be a useful strategy. For example,

SW: That's what worries me about asking it every three months, for some of these things that are really difficult, I mean maybe you just have them look over it, kind of like you do when you go back to the doctor and they say "has anything changed?"

RN: To know when that interval is, and to know who it is...Novant right uses (built in reminders) that fire, but ...they're overused and sometimes overlooked... So I think to get that right tool ...so you know that it's time ...and someone (will) take care of that, would be a bigger challenge.

RN: ...when they come in for off-therapy...we pull the off-therapy road map ...make sure that they have everything...once that awareness is there, then we can go, “Oh great!”

**Resource book.** One of the most discussed strategies to improve staff confidences to perform psychosocial screening was a resource book. Compared to a Pediatric Advanced Life Support (PALS) curriculum, this resource book could provide staff information about “what to do when” and “how tos” for addressing psychosocial distress. Additionally, education and practice/role play were mentioned as strategies.

MD1: ...perhaps set up a, kind of like we do PALS, we practice. If someone’s heart stops, or they stop breathing, we know where the crash cart is...If someone says, “I’m not doing well, I want to hurt myself, or I want to hurt someone else” that we have a process, ...a plan, a development.

RN: ...you could always have a resource for them to go to and say, “Well gosh they’re disclosing this really private matter to me, I really don’t know what to do with this information.” Maybe it’s just educating the nurses about what they do...

**Consulting with other programs.** Although only mentioned once, one strategy mentioned was to seek advice from the neighboring hospital regarding the logistics of implementing the PAT, making referrals and following-up.

SW: ...brainstorming with people who are already using (the PAT), finding out what are the benefits...the barriers...we are a small clinic, how would you recommend that we start out?

Overall, the strategies identified focused on ways to build the program prior to implementation. These strategies were detailed and specific to this clinic and are outlined in Table 2.

**Table 2:** Barriers and Strategies Identified

Barriers	Strategies
<p><b>Patient/family barriers</b></p> <ul style="list-style-type: none"> <li>• <i>Ability to participate</i></li> <li>• <i>Reading level/language barrier</i></li> <li>• <i>Willingness to participate</i></li> <li>• <i>Fear of stigma</i></li> <li>• <i>Time</i></li> </ul> <p><b>Staff barriers</b></p> <ul style="list-style-type: none"> <li>• <i>Time</i></li> <li>• <i>Lack of training and confidence</i></li> <li>• <i>Buy-in</i></li> <li>• <i>Ownership</i></li> </ul> <p><b>Contextual Factors</b></p> <ul style="list-style-type: none"> <li>• <i>Resources</i></li> <li>• <i>Clinic size</i></li> <li>• <i>Documentation and confidentiality</i></li> </ul> <p><b>Barriers Related to Screening Tool</b></p>	<p><b>Appeal to longstanding professional values</b></p> <p><b>Universal screening &amp; formalization of screening process</b></p> <p><b>Team approach</b></p> <p><b>Protocols</b></p> <ul style="list-style-type: none"> <li>• <i>Timing of screen</i></li> <li>• <i>Screening modality</i></li> <li>• <i>Organized approach to referrals</i></li> <li>• <i>Reassessment guidelines</i></li> <li>• <i>Resource book</i></li> </ul> <p><b>Consult with other programs</b></p>

## **CHAPTER 6: DISCUSSION**

The purpose of this project was to identify barriers and facilitators to implementing psychosocial distress screening in a small pediatric oncology clinical program and then to use these findings to inform the development of an implementation plan. Four overarching thematic barriers were discovered (e.g., patient and family barriers, staff barriers, contextual factors, and barriers related to the screening tool). Additionally, five facilitators, or strategies, to improve implementation were identified (e.g., appeal to longstanding professional values, universal screening/formalization of screening, using a team approach, building protocols, and consulting with other programs that had successfully implemented screening).

### **Patient and Family Barriers**

Five sub-themes were determined regarding the patient and family specific barriers (patient/family ability to participate, reading level and/or language barrier, willingness to participate, fear of stigma, and patient/family time). Consistent with previous work, the family and/or patient's willingness to participate was a considerable barrier in adult studies (Dilworth, Higgins, Parker, Kelly & Turner, 2014). Additionally, fear of stigma was also identified in adult studies, which led to the purposeful renaming the activity to "distress screenings" rather than "psychological screening" (Dilworth, Higgins, Parker, Kelly & Turner, 2014). Further, staff anticipated that parents would be innately protective of their children and continuously concerned with perceptions about their child and their family, and thus may avoid

answering honestly on the screening tool, especially within the first few weeks of meeting a new team.

Patient and family time was also identified as a barrier, and although previous examinations of psychosocial screening of adults with cancer did not specifically address patient time, this finding can be considered consistent with the literature in terms of the broad findings of time as a barrier (Mitchell, 2013). Though the screening tool may not take more than 10-15 minutes to complete, time is a scarce resource for parents of children with cancer, as they try to maintain usual routines for siblings and continue working to provide insurance and/or financial resources for their family.

Two other themes emerged regarding staff views on potential barriers for patients and families: the patient/family ability to participate and their reading levels and/or language barriers. Interviews with pediatric oncology staff identified that the patient/family may not be able to fully participate due to distress related to the child's cancer diagnosis as a distinct factor. Given evidence that the diagnosis of cancer in a child can be highly distressing and potentially traumatic for parents (Barrera, et al., 2014; Kazak, et al., 2011; Wiener, et al., 2006), this barrier could generalize to other pediatric oncology programs. Interestingly, the psychosocial distress that screening aims to identify and address can inhibit parent participation in said screening. This could cause under or over-reporting by the parents and requires thoughtful determination of re-screening or reassessing timelines. As one nurse had mentioned, it is necessary to screen patients and families at different points during the illness trajectory to gather all necessary information. Additionally, this may build a case that screening should not be performed within the first few days following diagnosis.

Lastly, while reading levels and/or language barriers were not previously addressed in the adult literature, this finding may also extend to other pediatric and adult oncology settings particularly in settings that serve patients and families vulnerable to health disparities (Office of Disease Prevention and Health Promotion, 2017). Although using a translator may not always be easy or efficient for staff in terms of their time, this resource is essential to providing equitable care to all patients and families, including equitable access and informed decisions about enrollment in clinical trials. The PAT is available in the Spanish language, but other languages would require a translator to read the English language form of the tool and record the parent's responses. Additionally, even if the screening tool is translated into the family's preferred language, the parent's health literacy level will likely influence whether s/he can comprehend and respond meaningfully to the PAT items (Centers for Disease Control and Prevention, 2016). If the parent cannot read or comprehend the meaning of the tool, the screening will not be useful.

### **Staff Barriers**

Four sub-themes of staff barriers were identified through the interviews with participants (e.g., time, lack of training and confidence related to screening, buy-in, and lack of ownership of the screening process). Consistent with the literature (Mitchell, 2013), staff time was repeatedly addressed in the interviews. In a context where many tasks are time-sensitive, staff can feel overwhelmed by the amount of work required within a given time frame. Adding new processes not initially understood or not perceived as important can be a challenge. Even though most staff verbalized that this screening was important, that did not change the reality of the multiple competing demands on their time. Additionally, also consistent with previous literature (Mitchell, 2013; Dilworth, Higgins, Parker, Kelly & Turner, 2014), staff reported concern about their ability to administer the PAT and the subsequent training needed, and feeling inadequately



prepared to evaluate the results and address them as indicated. Time and lack of training/confidence can be related to one another as a feeling of inadequacy often correlates to a longer time to accomplish a task (Mitchell, 2013). Thus, time and lack of confidence/training could be addressed by building protocols and related resource materials that enable the staff to build their knowledge base and confidence related to screening. This will be discussed in greater detail in the strategies section.

Although not unique with regard to practice innovation (Rogers, 2010), staff buy-in, resistance to change, and feelings of already providing adequate care has not been previously identified in the literature about psychosocial screening implementation in oncology settings. Theories of change (e.g., Diffusion of Innovation (Rogers, 2010), Theory of Planned Behavior (Ajzen, 1991) have been developed to understand how people and settings change over time and inform implementation of practice improvements. Also, although subjective, the staff felt that they provided adequate psychosocial screening and care to their patients. This perception alone can be a source of resistance to change.

Lastly, a largely noted staff barrier was lack of ownership of the new recommendation and its implementation. This barrier was not addressed in previous literature, but may be fundamentally due to the fact that previous work was performed in large cancer centers that may be better resourced and thus more advanced in terms of psychosocial care provision (also see the next section which discusses contextual factors). The burden felt by the social worker, who is solely responsible for addressing the psychosocial needs of the entire pediatric hematology and oncology population served by this program, was tangible in interviews with her as well as with staff in other roles who viewed screening as primarily the social worker's responsibility. She

would require other staff members to help take ownership of the screening process and further assessment, which was not something that staff mentioned they were necessarily willing to do.

### **Contextual Factors**

Three contextual factors and/or barriers were discovered through the interviews (e.g, resources, clinical program size, documentation and confidentiality of results). These factors can be viewed as barriers or simply as areas to be addressed in subsequent PDSA cycles. While specifics are unique to the clinic, the broader issues are consistent with the literature and may be generalizable to other settings. For example, lack of resources was previously reported in adult literature as a barrier to implementing psychosocial screening (Deshields, Zebrack, & Kennedy, 2013). Lack of resources made it difficult for screening implementation, as needs were discovered but could not always be appropriately addressed. One of the most significant differences between pediatric as compared to adult oncology is that children overall rely on their parents for care, and a parent's ability to perform clinical tasks and otherwise support the child can affect the child's treatment and treatment outcomes. For example, a mother with extensive substance abuse or history of suicidal ideations may need referral for full assessment and treatment, yet the clinical program focuses on the child and specifically on the child's cancer. And while the child cannot be treated in silo, the expertise of the pediatric oncology staff is not adult mental health. As a result, some issues identified through psychosocial screening can be difficult for clinic staff to address and thus they may prefer to not screen. These issues must be discussed and contingencies explicated going forward toward implementation.

Another contextual factor was the small size of the clinical program. While the small size of the clinical population rendered screening more feasible and promoted interdisciplinary communication, smaller size was also associated with fewer resources, specifically human

resources and private space. Additionally, the small nature of the clinic has fostered close and protective relationships between the staff and patients and families. In this, staff tended to be protective over the idea that the PAT may make some families feel uncomfortable. This protectiveness also led into another noted contextual barrier: documentation and confidentiality.

Due to the increasing need to document care and findings, discussion around how documentation would be performed caused concern with staff, specifically related to the sensitive nature of some of the PAT items. Furthermore, this clinical program uses an EMR that allows patient records to be accessed by anyone within the system. This means that PAT results and actions taken would be readily accessible to the patient's primary care provider, consulting physicians, and so on. Concerns about documentation of sensitive issues related to psychosocial screening are not apparent in either the adult oncology literature or in pediatric oncology literature specific to the PAT. Few tools are as comprehensive as the PAT, and the comprehensive nature of the PAT is what identifies the sometimes sensitive, yet important, information. Also, the PAT is currently available only in paper form, yet the charting system in most pediatric oncology settings is an EMR. This would mean that for the PAT to become part of the chart, the paper form would need to be uploaded into the media file, which is not always a frequented section of the EMR. Staff felt concern that the tool may be "lost" and then "found" on an audit without an appropriate link to documentation on how issues or concerns were addressed. Of note, one of the requirements of the recommendation is that the patients and families are screened and the result of these screens and their follow-up is documented in the patient's chart (Pirl, et al., 2014). If the clinic chooses to use the PAT, copyright approval may allow for the tool to be built into their EMR, which may reduce some of these concerns.

## **Barriers Related to Screening Tool**

Although the PAT was the screening tool used in this project, this tool is not required. Some staff expressed feelings that the tool was too lengthy or too comprehensive, yet lacked room for explanation. Shorter, less comprehensive pediatric distress tools are available and a different one could be discussed and agreed upon within the clinic.

## **Strategies for Addressing Potential Barriers**

Despite the number of barriers and contextual factors identified through the interviews, staff discussed strategies for implementing a psychosocial distress screening program. In total, five main strategies were identified (appeal to longstanding professional standards, universal screening and formalization of screening process, using a team approach, building protocols, and consulting with other programs). Only one - building a protocol - was cited in previous literature (Mitchell, 2013). This may be particularly appealing within the pediatric oncology setting due to the familiarity of staff with the use of protocols to guide both medical and supportive care. For example, pediatric cancer treatments are generally in the form of protocols with distinct roadmaps for treatment. These protocols extend into survivorship and have specific task lists for specific treatments. Additionally, emergency protocols for basic and advanced life support (BLS and PALS) are both required and routine education for pediatric oncology health professionals.

Healthcare providers are routinely taught that taking care of the patient includes addressing not only their medical/physical needs, but also their emotional and spiritual needs. Generally, people choose healthcare roles in an attempt to help sick or hurting people. Even further, those who choose to work with children with cancer and their families understand that they are meeting these children and their families during crises. This, combined with the longstanding professional values of providing holistic care for patients and their families, is a

strategy that can be used to help explain and bring relevance to the need for psychosocial distress screening within the clinic. Although the screening would still be an additional task for staff, using this approach may bring clarity to staff.

Additionally, a strategy commented on more than any other, was making the screening process formal and universal for all patients and families. This was not discussed in previous literature and may be due to prior implementation of this universal process. In context of this clinic, a prior attempt to build a psychosocial program failed, which many attributed to its “optional” status. While this study looks specifically at implementing a screening tool, staff came from an experience where there was significant confusion around how their role applied to psychosocial care, and who would receive this care. Thus, this may not be an issue in other settings but may be motivated by previous experiences for this clinic. This strategy is in line with the recommendation that all patients and families are screened (Pirl, et al., 2014) and may help bring clarity and normalization to the program for both staff and families.

Another new theme that emerged was building into clinic processes that are already in place and using a team approach to implement this program. As noted, there is only one social worker in this clinic. Therefore, her limited time and manpower would need to be supplemented by additional staff. This strategy may be specific to this clinic due to its small size and lacked affiliation with a larger facility and/or academic facility with more manpower. Staff members from other disciplines commented that they could help, but most verbalized that they may not be the best suited. Despite holistic care education, staff already felt that they were inadequately prepared to address concerns discovered on the PAT. Thus, requesting volunteers to be leaders in helping the social worker perform the necessary screens or help with scoring and providing these staff members with additional education may be a viable strategy. Using this team

approach may reduce the need for one specific “owner” of the program moving forward; rather a leader may emerge but the team is consistently involved in the process and hopeful success of the program.

One of the most in-depth strategies discussed in the interviews was to develop protocols around screening. Specifically, five subthemes were identified (timing of screening, combined assessment or filling out tool prior to meeting, “go-to” referrals, follow-up and reassessments, and a resource book). This is not a novel finding, as previous work in adult settings found that screening implementation was more effective when algorithms were in place for mandatory referrals (Mitchell, 2013). Additionally, most medical therapy for children with cancer is protocolized, thus the clinic staff is very comfortable with following protocols. However, the recommendation regarding psychosocial distress screening does not detail when or how screening should be performed or what should be done with the results. This leaves a “grey” area that can be very anxiety producing for staff as they move towards improving care for their patients, especially staff in a clinical area that has advanced medical outcomes through protocolized treatment regimens. While views differ on what the protocols should be, ultimately the clinic would need to decide as a team what is the most important way to implement the recommendation and what would work best with their unique population. For example, staff was concerned about the time it would take to perform the screening tool, yet did not necessarily want the family to fill it out alone and have the results scored and evaluated at a later time. The benefits and consequences to each choice would need to be examined and decisions made, using the previously mentioned team approach. Once protocols were in place, this may help reduce discomfort in staff performing these screens, give them insights for follow up and what to

expect, and reduce the amount of time they would need to spend searching for answers they would not otherwise know.

One way to help build protocols, and another strategy mentioned, was meeting with other programs that currently use the PAT to screen patients and families and getting feedback on their experiences. This may help alleviate some of the stress of the “unknown” and get insight into how protocols could be built to address the needs of this clinic. This was not mentioned in previous literature, but sharing knowledge is not a new concept in general. For other small communities that have access to staff at larger facilities, this may also be an effective strategy to employ. See Table 3 for relationships between barriers and strategies.

**Table 3:** Potential Strategies for Identified Barriers

<b>Identified Barrier</b>	<b>Potential Strategy for Specific Barrier</b>
<i>Patient/family ability to participate</i>	Allow for timing of screen to be within 1-2 weeks of diagnosis, but not within the first few days
<i>Reading level/language barrier</i>	Translator, screening modality should include staff performing screen with patient/family
<i>Patient/family willingness to participate</i>	Universal screening, part of holistic care
<i>Patient/family fear of stigma</i>	Universal screening, part of holistic care, build reassessment protocol to factor in for potential initial information withholding
<i>Patient/family time</i>	Consulting with previous families, build protocol to aid in efficiency

<i>Staff time</i>	Team approach, build protocol to aid in efficiency, consult with other programs
<i>Staff lack of training/confidence</i>	Organized approach to referrals, resource book
<i>Staff “buy-in”</i>	Appeal to longstanding professional standards
<i>Staff ownership of process</i>	Team approach
<i>Resources</i>	Organized approach to referrals, resource book
<i>Clinic size</i>	Universal screening/formalized process to help reduce protective feelings
<i>Documentation and confidentiality</i>	If able, building into EMR. Making PAT a “locked document” within EMR.
<i>Barriers related to the screening tool</i>	Staff can choose to use the PAT or find another preferred tool

## Next Steps

Each of the themes that were discovered in adult oncology settings regarding barriers and facilitators to implementing a psychosocial distress screening program were reported in this study, in addition to seven barriers and four strategies. Moving forward toward implementation plan, the findings regarding the barriers and facilitators identified by the participants from this clinic should be presented to them in summary form prior to initiating subsequent PDSA cycles.

While each PDSA cycle is relatively short, the clinic must understand that building this program may take time. Due to this, the clinic staff will need to “study” the results discovered in



the data they provided, and determine how to “act” moving forward. Using the strategies that they identified to address the identified barriers is a necessary step toward successful implementation. Therefore, finding team leaders who are able to help implement screening and using those leaders to help build protocols will be useful. Additionally, the participants will need to “plan” before moving into implementation. They will need to follow-up with the strategies they suggested (e.g. speaking with previous patient families, consulting with other families) to help prepare them for building the protocols they need.

Further work should evaluate how long it would take to build this program from the ground up, as this clinic is doing. Additionally, after implementation of the psychosocial distress screening program, further studies should evaluate the effectiveness of the implementation strategies, how these strategies can be used in other clinics with their own unique barriers and facilitators, and how the PDSA cycles can be reformed to help improve efficient implementation.

### **Limitations**

Limitations for this study include the small number of interviewees who provided data that may not be generalizable to other pediatric oncology clinics, particularly those that serve a larger population and have greater resources and/or academic affiliations. Also, by using convenience sampling, all staff at the clinic may not have had their views explicitly explored. Additionally, the project leader had prior relationships with many of the staff members due to the inpatient nursing work previously performed. Although the project leader did not work in the clinic specifically, she had interactions with the staff on multiple occasions through shared patients. This may have given staff a level of comfort with sharing, but may have inhibited others. Strengths include that no prior studies have focused on implementation barriers and facilitators within the realm of a small pediatric oncology clinic.

## APPENDIX A: COMMUNICATION WITH PARTICIPANTS

### **Request for participation in a practice improvement project**

*“Barriers and Facilitators to Implementing Psychosocial Distress Assessments in the Pediatric Oncology Setting”*

### **Background and purpose**

This is a request for you to participate in a practice improvement project that intends to assess barriers and facilitators to implementing psychosocial distress assessment recommendations in your clinic – the St. Jude Affiliate Clinic.

### **What does the study entail?**

Data will be collected through interviews with direct care providers from every interprofessional team including:

- Counselors
  - Child life specialists
  - Physicians
  - Nurses
  - Nurse Practitioners
  - Social workers
- 
- ❖ Interviews will take between 15-20 minutes to complete and will include questions related to personal views and experiences around psychosocial distress in your patients and ways to improve their care.
  - ❖ With your permission, your interview will be audio-recorded.
  - ❖ The project leader will come to your clinic to do the interview and will be available on multiple different days. Interviews will be on a scheduled or drop-in basis depending on the needs of the clinic, or can be over the phone before or after clinic hours.
  - ❖ When your interview is completed, you will be given a \$10 gift card to thank you for your help with the project.

QUESTIONS OR INTERESTED IN LEARNING MORE ABOUT THIS STUDY?

Please call or text Mercedes Stanley at 704-904-4450 or email us at [PATstudy@unc.edu](mailto:PATstudy@unc.edu).

# *Will you please help with a practice improvement project?*

## Who?

Direct care providers at the St. Jude Affiliate Clinic

## What?

Tell your ideas about family psychosocial distress screening in a 15-20 minute interview and receive a \$10 gift card in thanks!

## When?

At your convenience

## Where?

The project leader will come to you!

## Why?

Improve care for your patients and add to knowledge on this important topic.

*If you would like to participate, or have further questions, please contact project leader Mercedes Stanley at this email address:*

*[PATstudy@unc.edu](mailto:PATstudy@unc.edu)*

## **APPENDIX B: SEMI-STRUCTURED INTERVIEW GUIDE**

1. What is your level of education and/or certification(s)?
2. How long have you worked in your profession?
3. How long have you worked specifically with pediatric oncology patients?
4. What have you heard about the psychosocial distress screening recommendations?
5. Have you noticed ways that distress affects your patients and families? If so, how?
6. In what ways does psychosocial distress directly relate to their treatment?
7. Do you feel that your professional group should play a role in managing distress assessments? What role would you be willing to play?
8. I've provided a copy of the recommendations and the psychosocial assessment tool (PAT); what difficulties do you foresee that may make implementation difficult?
9. What are things that might make implementation easier? Are there current processes in place that may already be well formatted to help improve the flow of this new process?
10. What supportive services do you know of that can be used to help families that are categorized as high-risk? Do you think these services are currently over-used or under-used?
11. Is implementing a psychosocial distress screening program important for your patients?
12. Based on the recommendations for this program, a psychosocial committee must meet on a regular basis and include participants from multiple disciplines. Would you be willing to be a part of this initiative?

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