HEALTHCARE COMMUNICATION BARRIERS ENCOUNTERED BY CHILD LIFE SPECIALISTS

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By

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APPROVAL

The undersigned, appointed by the dean of the Graduate School, have examined the thesis entitled

HEALTHCARE COMMUNICATION BARRIERS ENCOUNTERED

BY CHILD LIFE SPECIALISTS

Presented by Kendall Malkin,

A candidate for the degree of Master of Science,

And hereby certify that, in their opinion, it is worthy of acceptance.

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Professor Russell Ravert

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Professor Colleen Colaner

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HEALTHCARE COMMUNICATION BARRIERS ENCOUNTERED BY CHILD LIFE SPECIALISTS

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ABSTRACT

Communication in the healthcare setting can be complicated due to various reasons such as language barriers or complex medical terminology, yet effective communication is necessary for overall care and safety of an individual's well-being. There is an abundant amount of research about communication barriers by a variety of healthcare professionals, but there is limited research by child life specialists. This research study explores the perspective of communication barriers by certified child life specialists (CCLS) in the United States using the frameworks of transactional model of communication and critical incident technique. A total of 129 child life specialists completed an online survey identifying common communication barriers when interacting with patients and families. Nine participants from the survey responses were invited and completed follow-up interview sessions, further examining specific barriers encountered and the ways CCLS worked to address them. Findings were compared with previous research on healthcare communication barriers encountered by hospitalists and other multidisciplinary team members. The results will be useful for child life specialists working to increase patient satisfaction and promote family-centered care.

CHAPTER 1: LITERATURE REVIEW

Healthcare Communication Barriers Encountered by Child Life Specialists

About one out of six discharges from hospitals in the United States were for children aged 17 years and younger in 2012, and there were over 5.8 million hospital stays by children and adolescents under 17 years old, for an average of 4 days each (Witt, Weiss, & Elixhauser, 2014). The healthcare setting is often a stressful place for children and families with an unfamiliar environment, medical jargon and language, and meeting multiple healthcare team members from nurses to physicians, and from social workers to child life specialists. The role of a certified child life specialist (CCLS) is to help reduce stress and anxiety within the healthcare setting by using developmentally appropriate interventions such as procedural preparation and therapeutic play (Association of Child Life Professionals [ACLP], 2018). CCLS have an educational background in child development and psychology that supports use of developmentally appropriate language with children of various ages. Even so, there is an abundant amount of research from various healthcare professionals indicating that communication is a large issue in the healthcare setting due to various reasons such as language barriers and complex medical terminology.

Transactional Model of Communication

The current study is grounded in a theoretical framework of the transactional model of communication. The transactional model of communication (see Appendix A) states that communication is more than just sending and receiving messages, but being able to communicate to create relationships. Participants who send and receive messages are referred to as communicators. Communicators use communication to construct social

realities within relational, cultural, and social contexts. These contexts have underlying rules and norms for communication ("The Communication Process," 2016). For example, a doctor has the underlying norm to communicate medical information to a patient concerning his or her health, whether it is conveyed clearly or not. The patient will then send verbal and nonverbal messages if he or she receives the message. If there is "noise" where the message is sending or being received, that could be interpreted as a communication barrier. This theory can help to then identify where that communication barrier takes place when conversing and building a relationship between a child life specialist and a patient and family.

Healthcare Communication Barriers

Before understanding the effects of communication barriers in the healthcare setting, it is important to also identify and understand the types of communication barriers found in healthcare settings. Healthcare communication barriers must be recognized and addressed to deliver efficient healthcare services and improve patients' health statuses (Tsoh et al., 2016). Many patients, regardless of language barriers, have a common issue of understanding complex medical jargon from their doctors as many do not take the time to explain the vocabulary in simple terms (Korsch, Gozzi, & Francis, 1968; Gulati et al., 2011; Rosenberg et al., 2017). Additionally, healthcare settings add a level of stress and anxiety that can make it hard for patients and families to process new information and be able to comprehend it at the same time (Gulati et al., 2011). Information comprehension and mental ability can be compromised by stress, resulting in a communication barrier for many patients and families. Thus, one role of CCLS is to

then further reduce stress for patients and families and promote effective communication towards family-centered care.

Patient- and Family-Centered Care

Patient and family-centered care is the overarching care goal of many healthcare systems today by establishing mutually beneficial partnerships between patients and families and their healthcare team members (Owen, 2016). The ideal purpose of this type of care is to include patients and families in all treatment and care decisions. Family-centered care encourages patient autonomy as required under the Patient's Bill of Rights (American Health Association, 2003). It is crucial for healthcare providers to currently focus on overall health, including socioemotional and mental health. It is common to have physician-centered communication when there are language barriers involved, and this decreases patient satisfaction (Diamond et al., 2008; Fernandez et al., 2010). Some healthcare settings are working to replace the practice of physician-centered health care with a patient and family-centered care approach, with an increased emphasis on forming relationships to increase patients' overall satisfaction and health. When care is increasingly patient- and family-centered, there is more frequently shared communication between patients, families, and healthcare providers. Having patients' and families' perspectives is essential when making medical decisions as they are part of the healthcare team (Schyve, 2007). CCLS also focus on building therapeutic relationships with patients and families, and often encourage, validate, and support them in voicing their decisions in their own healthcare. CCLS are often advocating for patients and families when communicating with the medical team to strive towards effective family-centered care.

Previous Research

In their research with hospitalists (doctors that work in the hospital), Rosenberg and colleagues (2017) identified a set of specific communication barriers those healthcare workers experienced, including frequent handoffs (e.g. shift changes), lack of time, and lack of long-term relationships with patients (Rosenberg et al., 2017). Because there is limited research about CCLS and their relationship and communication with patients and families, the current study was designed to use the measures Rosenberg's (2017) study of doctors to allow comparison with experiences of CCLS.

According to the Association of Child Life Professionals (2018), a nationally recognized child life organization, one of the values is communication in that child life specialists are dedicated to enabling all forms of communication by "observing, listening, and facilitating communication with those who may be misunderstood or who need support in order to be heard." Based on this value of communication linked with CCLS and their values of building therapeutic relationships, CCLS should be considered in their role in reducing communication barriers in the healthcare setting.

Critical Incident Technique

Flanagan's critical incident technique (CIT) was a guiding framework for the interview questions in the current study. The CIT collects information about people's behavior in specific situations in an efficient manner using concentrated questioning (as cited in Bjorklund, 1999; Irvine, Roberts, Tranter, Williams, & Jones, 2007). The current study used this approach to further identify and understand the specific situations discussed and found critical by both the interviewee and researcher. CIT helped identify the "noise," or communication barrier, experienced in particular situations by the CCLS,

from a transactional model of communication perspective. CIT also provided steps in order to address and reduce those communication barriers.

Research Questions

With limited research about the relationship and communication between child life specialists and patients and families in the healthcare setting, this current study proposed several research questions.

Research Question 1: What are the most challenging communication barriers that child life specialists identify and encounter in pediatric healthcare settings with patients and families?

Research Question 2: Does a child life specialist's approach to communication barriers vary based on the number of years of experience? More years of experience as a CCLS is expected to be positively associated with lower communication barrier scores.

Research Question 3: What do child life specialists do to reduce communication barriers?

CHAPTER 2: METHODOLOGY

Methods

A mixed methods design was utilized in this study, collecting both quantitative and qualitative data from certified child life specialists. Mixed methods research can provide an original combinational approach to address the complexity of different factors within healthcare services (Fetters, Curry, & Creswell, 2013; Morgan, 1998). Using an explanatory sequential design, an online survey was distributed to CCLS participants, and then a number of the participants were chosen in follow-up interviews. The participants were selected and invited in follow-up interviews based on their open-ended responses within the top four themes of communication barriers identified. The survey, or the preliminary quantitative method, was to establish initial results to pursue in depth with a qualitative follow-up interview to further evaluate and interpret the results (Morgan, 1998).

Sample and Recruitment

Approval was obtained from the University of Missouri's Institutional Review Board (IRB). A set of potential participants were randomly selected from a comprehensive directory of child life programs available from the Association of Child Life Professionals—a national child life organization—for members, including the researcher. The directory was used to generate an Excel spreadsheet to organize the data by programs' name and location within the United States (1) and other countries (0), include email addresses for contact information, to randomly select potential participants. There are currently 525 child life programs all over the world registered with the Association of Child Life Professionals, and approximately 450 of those programs reside

in the United States. The objective was to collect responses from a quarter of those U.S. child life programs in order to generalize findings of child life specialists with the anticipated goal of nearly 70% response rate. A set of 172 child life programs was randomly selected (www.randomizer.org). Invitations were then sent to the contact person/email address at each of those 172 programs, and included a link to the survey to participate via email. See Appendix B for the e-mail that was sent to potential participants. After the initial invitations sent, 32 of these email addresses failed to reach these potential participants. An additional 32 invitations were sent, with only six failing to reach these additional potential participants. Altogether, 166 total emails were sent successfully.

After 10 days, a reminder e-mail was sent to potential participants to complete the survey. Emails contained a link to an informed consent form, and continuing on from that form led to a Qualtrics-based online survey. The informed consent form can be found in Appendix C.

Survey/Instrument

The online survey contained a set of 16 questions. A set of demographic items asked participants what hospital and unit(s) the CCLS works in, and where the hospital is located. The information provided were kept anonymous and confidential, but was necessary to keep track of the response rate and avoid sending duplicate requests.

A set of items regarding communication barriers was adapted from Rosenberg's (2017) study of communication barriers identified by hospitalists. Wording was revised on several items, such as replacing "hospitalists" with "child life specialists." Several questions were eliminated from the original measure because they focused on serious

illness and palliative care, and were not relevant to this study. Respondents were asked to rate the set of 12 communication barriers on a Likert scale ranging from 1 (*not a barrier*) to 4 (*extreme barrier*). A set of seven open-ended questions, created by the researcher for this study, asked the participants about past interactions with patients and families and to identify communication barriers (See Appendix D).

Follow-Up Interviews

Purposive sampling was used to select 13 participants who completed the survey, and were then invited to further participate in interview sessions. Email-based interviews following the completion of the surveys within the mixed-methods approach help to understand contextual factors and further explain survey results (Fetters, Curry, & Creswell, 2013). Using the CIT framework further researched the components of communication in the specific situations collected from the surveys, and whether or not the CCLS was able to reduce the communication barrier. Thirteen child life specialist participants were chosen based on their answers to the open-ended questions of the survey (i.e. having experienced at least one communication barrier with patients and families).

Given that a small sample size of well-selected interviewees can further generate crucial information for deeper analysis (Cleary, Horsfall, & Hayter, 2014), a goal was set to complete follow-up interviews with child life specialists who had completed the survey. The objective was to collect rich qualitative data from a sub-set of respondents regarding the approaches child life specialists implemented towards those reported barriers. Selection was made following initial analysis of results from the open-ended survey responses, completed to identify the most common communication barriers.

Participants were then selected and invited to complete follow-up interviews designed to further explore the four most frequently mentioned themes of communication barriers found in the open-ended survey responses. Interview timing was flexible based on the participants' preference and comfort level to promote effective communication with the researcher, and this was done via email. CCLS who voluntarily participated were informed and gave consent to the interview sessions, which were documented and kept confidential. The set of general interview questions, which had also included the individual's open-ended response, can be found in Appendix E.

Data Analysis

The data collected from completed surveys were downloaded into Statistical Package for the Social Science (SPSS) for coding and analysis. To investigate the quantitative data of the completed surveys, descriptive statistics were utilized such as frequencies, percentages, and mean scores. The section adapted from Rosenberg's (2017) study were analyzed to compare the results provided by hospitalists with those provided by child life specialists. Responses on each item were dichotomized based on the respondent's answers using the 4-point Likert scale. Answers were then clustered into two categories (not a barrier/minimal barrier, and extreme/moderate barrier) and assigned scores (0,1). This allowed for comparison with results from Rosenberg's (2017) study, who utilized a similar method.

Content analysis was utilized to analyze the qualitative data collected in the interview sessions with child life specialists. Content analysis is a method that analyzes written or verbal communication messages, and Cavanagh (1997) states that it is used to develop an understanding of the meaning of communication (as cited in Elo & Kyngas,

2008). Themes of communication barriers were identified from the results based on word items from the participants' open-ended responses using an inductive content analysis approach; this inductive approach organized the data to then create categories of the responses (See Table 4). This helps provide a further explanation and validation of reasons and beliefs stemming from the experiences of child life specialists when interacting with patients and families.

CHAPTER 3: RESULTS

Results

A total of 166 survey invitations were sent successfully. One hundred and thirty seven (137) participants began the survey, as shown in Phase 1 of Figure 1. Eight participants' responses were discarded for not meeting the criteria of at least 75% completion of the survey. A total of 129 responses met this 75% completion criteria of the survey. There was thus a 67% response rate, calculated as the number completed out of the total number of participants invited.

Sample Characteristics

The 129 participants in this sample were all certified child life specialists who work in a healthcare setting, such as a hospital or hospice care. Less than 5% of the sample had been working as a CCLS for less than one year. Over half of this sample (58.1%) had been working as a CCLS between a year to nine years. About a quarter of the sample reported having worked over 10 years, but less than 20 years. A little more than 10% of the CCLS sample had worked over 20 years. On average, many child life specialists worked about 10 years. The correlation between years of experience and overall mean barrier scores was not significant, $r = -.137$, $p = .121$. Further analysis of each individual barrier score in correlation to the number of years of experience also did not reach statistical significance.

CCLS were then asked to select one area of their healthcare setting in which they spend majority of their time. The largest group, 38% of the sample, reported working in inpatient acute care. Fourteen percent of the sample worked in outpatient emergency, and another 14% in outpatient ambulatory, which excludes radiology and pre-surgery. There

was about 10% of the sample that worked in pre-surgery, with another 10% who reported that they work in inpatient critical care. Radiology (6.2%) and other areas not common in the hospital like hospice and private practice (7.8%), were both reported separately as less than 10% of the sample.

Because child life specialists work with a wide variety of ages of children ranging from newborn to an adolescent up to 18 years old, participants were asked to select one age group they work with the most within patients and families. Over half of the sample (54.3%) reported working with school-age children most frequently. The next age group with the most responses were preschool children with over a quarter of the sample (27.9%). The sample reported less than 10% individually working the most with infants/toddlers or adolescents, which are both the youngest and oldest age groups. The characteristics of the sample can be found in Table 1.

Table 1

Sample Characteristics of Child Life Specialists

Characteristic	# (%)	Mean (*SD*)
Years worked as a certified child life specialist		9.6 (8.4)
Less than 1	5 (3.9)	
1-9	75 (58.1)	
10-19	33 (25.6)	
20-29	10 (7.7)	
30-39	6 (4.7)	
Areas worked by child life specialists majority of time		
Inpatient Acute Care	49 (38.0)	
Inpatient Critical Care	13 (10.1)	

Radiology	8 (6.2)
Pre-surgery	13 (10.1)
Outpatient Ambulatory (Excluding Radiology and Pre-surgery)	18 (14.0)
Outpatient Emergency	18 (14.0)
Other (i.e. Hospice, Private Practice)	10 (7.8)
Patients' age groups child life specialists work with the most	
Infants/Toddlers	11 (8.5)
Preschool Children	36 (27.9)
School-age Children	70 (54.3)
Adolescents	9 (7.0)

Note. Total responses = 129. Three respondents did not answer.

Barriers Reported by Child Life Specialists

Lack of time was found by respondents to be the highest barrier, as reported by almost 74% of the sample. This is about 30% greater than the next highest barrier, which is language barriers, reported at 43.4%, often found between CCLS and patients/families. More than a third of the sample (34.1%) indicated that a lack of a long-term relationship with patients to be the third-highest barrier. Three barriers were reported by over 20% of the respondents to be a significant barrier with lack of support from hospital leadership (28.7%), unrealistic expectations about care from multidisciplinary roles (24.8%), and difficulty finding information in the patients' medical records (21.7%). There were four additional barriers, reported by at least 10% of the respondents, and therefore not as significant. These were frequent handoffs between CCLS (18.6%), the emotional toll of goals of care discussions (14%), the lack of clarity about the CCLS' role (13.2%), and the differences in culture between patients/families and CCLS (10.9%). Less than 10% of the

sample ranked inadequate training (3.9%) and negative reactions from patients and families (2.3%) as significant barriers. The results of these reported barriers can be seen in Table 2.

The mean barrier scores did not differ by the areas where participants worked, $F(5, 113) = .223$, $p = .952$. Comparison of mean barrier scores by age groups using analysis of variance (ANOVA) did not yield statistically significant differences, $F(3, 122) = .116$, $p = .951$. Likewise, no statistical association was found between mean barrier scores and age groups based on the Spearman's Rho test for ordinal variables correlations, $r_s = .040$, $p = .660$.

Table 2

Frequencies (%) of Reported Barriers by Child Life Specialists

Barrier	Moderate barrier/ Extreme barrier	Not a barrier/ Minimal barrier
Lack of time	95 (73.6)	34 (26.4)
Language barriers between patients/families and child life specialists	56 (43.4)	73 (56.6)
Lack of a long-term relationship with patients	44 (34.1)	85 (65.9)
Lack of support from hospital leadership	37 (28.7)	91 (70.5)
Unrealistic expectations about care from other healthcare team members	32 (24.8)	95 (73.6)
Difficulty finding prior goals of care discussion details in the medical records	28 (21.7)	93 (72.1)
Frequent handoffs between child life specialists	24 (18.6)	103 (79.8)
Emotional toll of goals of care discussions	18 (14.0)	108 (83.7)
Lack of clarity about child life specialists' role in these discussions	17 (13.2)	110 (85.3)
Differences in culture among patients/families and child life specialists	14 (10.9)	115 (89.1)
Inadequate training	5 (3.9)	124 (96.1)

Negative reactions from patients and families	3 (2.3)	126 (97.7)

Note. Total responses for these items ranged between 121 and 129.

Themes of Barriers Found in Open-Ended Responses

In their surveys, 86 respondents provided an example of a professional experience involving a barrier interacting with patients and families. From all of the responses, ten themes were identified using inductive content analysis (see Table 3). Over half of the participants, or 53%, reported language barriers. Language barriers may result when verbal and written communication differ between patients/families and the healthcare team. One participant advanced in reducing language barriers by memorizing "a handful of phrases to introduce myself and offer normalization play in the most common languages at my facility…I have worked to develop comfort using interpreter (live and video streaming)." There was an overlapping sub-theme also found with the use of interpreters and language line services to alleviate the language barrier; many participants then further hoped to reduce this barrier by utilizing interpreting services in the future. Several participants also wrote in their open-ended responses to advocate in the future for an interpreter present as the child life role is perceived as "non-medical" and further misconstrued as nonessential.

The next most common theme was miscommunication with multidisciplinary roles of the healthcare team. About 13% of the participants reported examples of lack of communication or respect among the medical team and the CCLS, or with patients/families. Some respondents said that checking in and continuing to build rapport with staff members, patients, and families involved afterwards was helpful to change and reduce this barrier in the future.

Three additional themes of barriers with patients and families were identified by less than 10% of the sample. One theme (8%) regarded the role of the CCLS being misunderstood by the medical team, patients and families. To reduce this barrier, participants explained their role as a CCLS more in depth. One child life specialist stated collaborating with the child life department to identify different approaches with various departments to address the importance of our role. Educating or meeting with the medical team was also found beneficial.

Technology was another barrier with 7% of the sample stating that technology was used for services, such as video interpreters, or served as a distraction for patients and families. About 6% of the participants talked about comprehension as another themed barrier, in which patients and families do not understand the information provided. Time (5%) was a barrier for CCLS to build rapport or provide support for patients and families in a sufficient amount of time. Another theme not ranked as highly was stress, with 3% of the sample identifying this barrier that influences patients and families with successful coping and awareness of their situations. Two participants (2%) found that working with people of different communication styles can be a barrier to successful communication of their care of plan for the patient. Two barriers identified by 1% of the sample each was cultural, or when strong beliefs can interfere with care, and ethics, or the moral principles of the healthcare team that differs from the patients/families. A few ways to reduce some of these barriers include continuing to check in and build rapport with the patient/family and medical team. Examples of these ten themes can be found in Table 3 below.

Table 3

Themes Reported by Child Life Specialists in Interactions Involving Barriers

Theme	# (%)	Examples
Language Verbal and written communication different between CCLS and patients/families, or interpreter/language line used to alleviate language barrier.	46 (53)	• "Limited availability of interpreter or parental presence not there and child is too young to talk on an interpreter phone." • "I had an experience with a family that did not speak English where the interpreter was minimally helpful and did not interpret my preoperational teaching well. The patient seemed to become more confused and anxious due to this barrier."
Medical Team Miscommunication Lack of communication or respect between multidisciplinary roles and/or with patients/families.	11 (13)	• "The medical staff did not provide CLS with pertinent and necessary information prior to calling CLS for consult or intervention (procedural prep, distraction, support and/or coping) and it impacted the intervention and consult's success with pt and family." • "Providers will put in a consult for bereavement support without first speaking with the family about their wishes."
Misunderstanding of Child Life Specialists' Role Multidisciplinary roles and/or patients/families did not know the role of a child life specialist.	7 (8)	• "[Parent] thought that a major part of our role was to allow parents to "check out" while the CCLS 'took the role of the parent.'" • "A outside physician described the child life specialist role as a bubble blower and the family did not understand how CL could help during a procedure."
Technology Technology used as services or a distraction.	6 (7)	• "Parent(s) spending too much time on phone/technology during staff interactions…Children who are unable to engage with social interactions due to too much technology use." • "Video interpreters cut out, usually must face the patient and family which is not ideal for a patient that has not seen their facial injury as of yet, and removes a level of intimacy when discussing difficult topics."
Comprehension Understanding and intake of information provided between speaker and receiver at developmentally appropriate levels.	5 (6)	• "Our patient population is often low functioning and have many risk factors present which can decrease their comprehension further." • "I have been faced with the challenge in which a family has low medical knowledge/experience and then other team members attempt to engage without allowing me time to prepare not only the patient but the parents prior to a procedure."
Time Measure of time within progress of events.	4 (5)	• "I had very little time to build rapport and was not completely sure what was the best way to explain a very complicated set of circumstances." • "We…have 30-45 patients a day so it makes it difficult to have long, meaningful interactions sometimes."

Stress A state of mental or emotional tension that results from demanding circumstances.	3 (3)	• "This was a high stress situation where the parent felt scared, angry, and uncomfortable with the entire hospital staff."
Different Communication Styles Communication styles or patterns that differs between at least two people involved.	2 (2)	• "The most common communication barrier I have with families is when the [patient]'s main caregivers are having difficulty communicating and agreeing on their child's course of treatment, behavior, discipline etc."
Cultural The ideas, customs, and social behavior within one society.	1 (1)	• "You cannot successfully alter a family's beliefs especially at a crucial time such as end of life. The support and acceptance from the religious leader/guide/community is far too strong to battle."
Ethics Moral principles that guides a person's behavior and thoughts.	1 (1)	• "Ethical dilemma versus honoring family's wishes…to not tell a child or siblings that he was imminently dying."

Note. Total responses = 86.

Follow-Up Interviews

Follow-up interviews were conducted with a sub-group of all survey respondents who had chosen to include their contact information for follow-up interviews (see Phase 2 of this study as shown in Figure 1). These follow-up interviews were used to further explore the four most common themes identified in content analysis responses (language, miscommunication with the medical team, misunderstanding of the child life specialists' role, and technology). The researcher used inductive content analysis to identify participants from these four common themes to further investigate why these themes were highly ranked. The goal of this type of analysis was to further investigate the most prominent themes that emerged from the interviews. Therefore, the method used to select participants involved identifying the most frequent themes, and selecting individuals proportionally from the eligible follow-up sample pool, or participants that have provided informed consent and volunteered contact information (n = 46). With the goal of ten interviews, selecting thirteen participants to conduct in follow-up interviews were picked in proportion to the open-ended respondents.

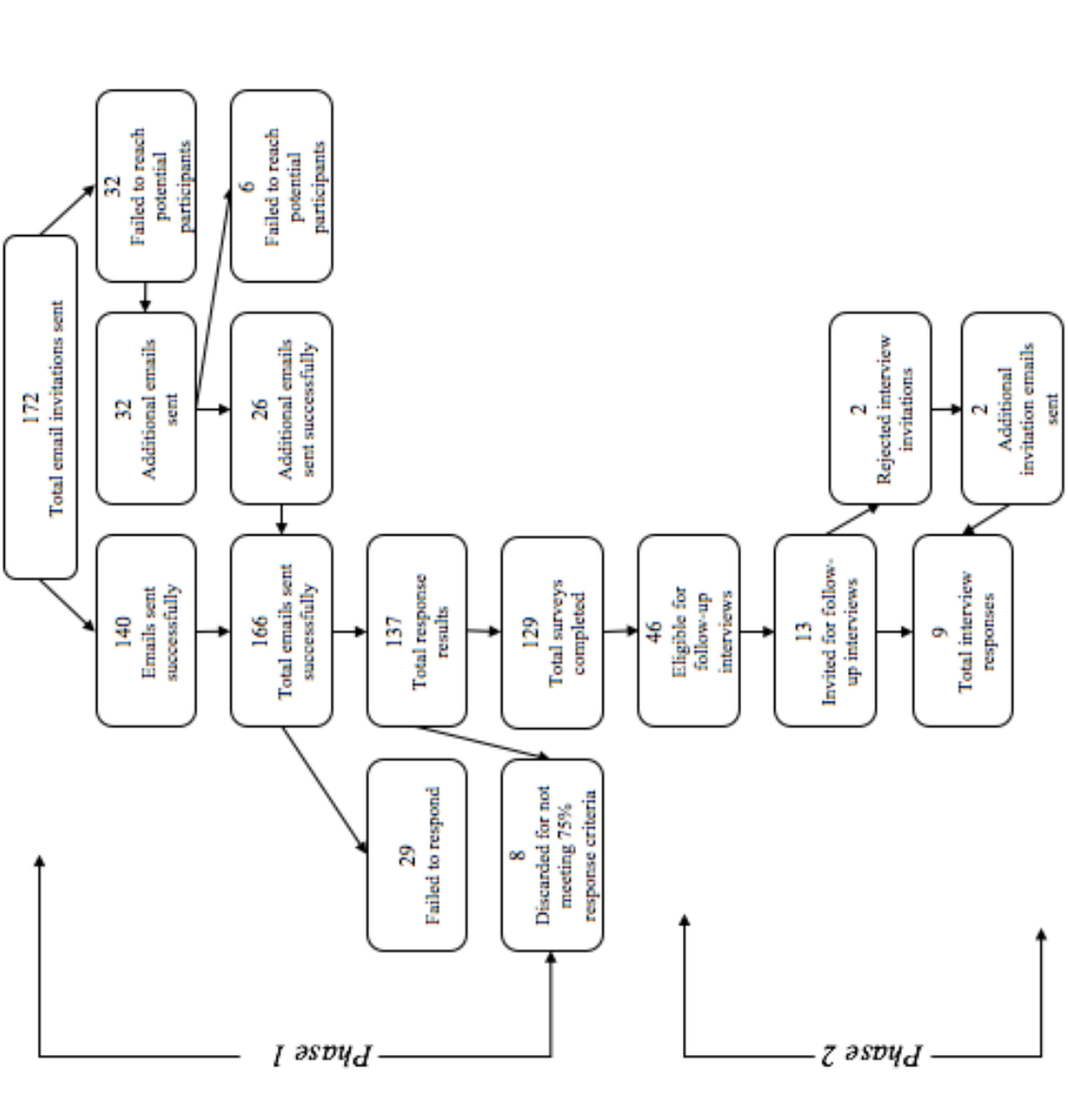
In the open-ended survey questions, about half of respondents identified and provided an example of a language barrier when interacting with patients/family. Thus, six participants were then selected to further contact and ask about language barriers and interpreter usage to proportionally represent half of the interviewee selections. Three participants were invited for an interview about their responses in terms of miscommunication with the medical team. Two participants were selected in their responses to technology usage, and another two participants about the barrier with their role as a child life specialist being misunderstood.

Therefore, a total of thirteen participants were recognized and invited to participate in the follow-up interview sessions via email. Two rejected the invitations, as one reported not having time and the other had an automatic email response being on extended leave from the hospital. Two additional interviewees were invited to participate. Altogether, nine CCLS accepted the invitation and provided more in-depth information about the situations they had discussed in their open-ended responses of the survey.

Questions were selected from a list in Appendix E, individualized towards each participant based on their survey open-ended responses. Select replies from these interviews are included in Table 3 with the top four themes. Several participants explained in depth how they reduced the barrier within their individual situation, including educating new employees or medical team members about the CCLS role. In addition, some learned from their situations for the future to further advocate for the CCLS role and also advocate for the patients/families.

Figure 1

Distribution of Number of Participants in Study



CHAPTER 4: DISCUSSION

Discussion

The purpose of the current study was to ask child life specialists to identify barriers in their communication with patients and families in the healthcare setting. By using a mixed methods design, multiple approaches were used to provide rich data to address the research questions. Results identified the types of communication barriers commonly experienced by CCLS, and indicate that mean barrier scores were similar regardless of CCLS' years of experiences, age groups CCLS worked with, nor the units CCLS work in. This means that regardless of the type of barriers experienced, they do not differ based on professional experience in terms of years or populations worked with. Of interest, the ranking significant communication barriers cited by participants differed between the responses to the Likert scale and the open-ended responses. One possibility is that the survey format itself influenced responses. However, a study done by Covell and colleagues (2012) showed that the distribution of measures used in mixed methods had no effect on the participants' responses. Therefore, it is unlikely that the barriers in the Likert scale portion of the survey did not determine the barriers participants cited in their open-ended responses.

Lack of time was found to be the greatest significant barrier out of 12 identified barriers for this sample as well as in Rosenberg's (2017) study. This indicates that both hospitalists and child life specialists agree that lack of time is the largest barrier in the healthcare setting. There was a lack of responses with approaches to further reduce this barrier, and future research is recommended. Technology was another significant barrier in the study that also lacked in ideal approaches to reduce this barrier.

The second most significant barrier found by CCLS was language. On the other hand, language barriers were not ranked as highly (ranked 9th) by hospitalists in Rosenberg's study. While ranked highly from this study's scale as the second most significant barrier, language was identified as the most common barrier by over half of the sample (53%) in their open-ended responses. In both the open-ended responses and interview sessions, some participants stated to advocate the need for more staffing of medical interpreters to further reduce this communication barrier.

Whereas over half of the hospitalists in Rosenberg's sample identified frequent handoffs (57%) to be a significant barrier, but was ranked not as significantly by less than 20% of child life specialists in this study. This may be possible due to typically smaller teams of child life specialists in the healthcare setting that may only have one position for one unit or share units, whereas there are multiple hospitalists in each area of the hospital, and cover through the nighttime.

Interestingly, hospitalists (39%) from Rosenberg's (2017) study ranked negative reactions from patients and families as a more significant barrier compared to CCLS (2.3%) in this sample, who identified this barrier as the least significant barrier. Speculations may be a possibility that child life specialists strive for more positive healthcare experiences, and typically advocate for patients and families to meet their needs and satisfaction. Another possible reason may be that crying is considered as a negative reaction, whereas child life specialists are educated to view crying as a coping mechanism. The perception of this emotion and other negative reactions as a communication barrier can greatly impact the relationship between the patient/family and the medical team, and further supports the transactional model of communication. This

model emphasizes the "noise" of a communication barrier, such as negative reactions or stress, that further impacts the relationship between the communicators, or in this role, the patient/family and the CCLS or hospitalist.

A unique theme identified in the study as a common barrier was the misperception of the child life role. The role of a child life specialist is newer to the healthcare field (established in 1982 with the Child Life Council; Association of Child Life Professionals, 2018). This specialty is not commonly known to the average person who may come in the hospital needing support and care, and are more familiar with the standard professionals of a nurse and doctor. In the survey, participants were asked if there were any barriers not mentioned in addition to the Likert scale of 12 communication barriers identified from Rosenberg's (2017) study. Approximately 15 respondents mentioned the lack of knowledge of the child life role, or that child life specialists are unable to meet all patient and family needs as they are understaffed. Therefore, this researcher speculates the need for more child life specialists and further education of the child life role. Some participants voiced that to reduce this barrier, it is necessary to advocate for the CCLS role, meeting and educating the medical staff, as well as finding different ways to explain the child life role to patients and families. One interviewee captured the need to spread awareness of the child life profession, "there will always be the need and opportunity for more education about our role and services we provide." Not only is education necessary for patients and families to fully support their needs, but also for other healthcare multidisciplinary roles. One participant expressed a common example among other titles of the role, "the CT [radiology] staff referred to child life as a 'glorified babysitter.'" Another participant reduced this barrier by speaking "at the

pediatric department head meeting where all outside physicians attended and I educated them on the child life program." Child life specialists utilize play therapy to help communicate with children at their developmentally appropriate levels. Play is found to facilitate coping, self-expression, healing, and learning, and is "vital to a child's optimal growth and development" (ACLP, 2018).

Limitations

There were important limiting factors to consider when interpreting the analysis of this empirical study. A limitation of the study is that the measure altered from Rosenberg's (2017) study has not been used before. To help address this, the survey was piloted with a convenience sample of one team of child life specialists from a pediatric hospital before distributing the survey and collecting data. The researcher used feedback from the sample, made up of seven CCLS, to improve clarity and accuracy of the questions prior to implementing the survey. Additionally, follow-up interviews were used to allow for further probing of the barriers.

Another possible limitation with this study was that there were low samples in several areas where CCLS work (i.e. radiology and pre-surgery) that could have limited ability to find statistical significance. Future researchers could design a study specifically to examine communication barriers by the units where CCLS work in. The researcher also encourages future research to conduct from the perspectives of patients and families in what they identify are communication barriers and what actions could be done to reduce communication barriers.

Conclusion and Implications

Improving communication efforts and reducing communication barriers, if any, are essential when interacting with patients and families in the healthcare setting for their own health and safety. One participant voiced, “Hospitals, especially bigger institutions, will always face some level of communication barriers. Keeping track of communication troubles can help down the road in creating solutions to these issues.” Considering the healthcare setting is a stressful place for patients and families, it is crucial for child life specialists to help provide support to reduce stress and anxiety and promote coping techniques. Child life specialists are also members of the medical team that help to maneuver communication and messages between the medical team and the patients and families. The researcher emphasizes the fundamental need of child life specialists in the healthcare setting, and one of the top themes in the study with the misconception of the child life role. A suggestion would be further education and awareness of the growing profession of child life specialists for healthcare administrators, medical staff, and the outside community.

Although research regarding communication barriers identified by other healthcare professionals exists, research from the perspective of certified child life specialists is limited. The current study might be used to support the importance of the role of a certified child life specialist. For example, some findings demonstrated that child life specialists encounter different levels of communication barriers than hospitalists (i.e. language and negative reactions by patients and families). Additionally, previous research has repeatedly highlighted the issue of communication barriers in the healthcare setting, but researchers do not suggest how to approach the problem. One interviewee

from the study said, “I think communication barriers will always exist in one form or another. I believe it comes back to making sure you give choices and pursue alternate avenues of communication.”

Hopefully, findings from this study will help to prepare child life specialists to identify and successfully approach communication barriers. Future research is necessary to recognize successful approaches to various communication barriers. The results of the study might be useful in establishing a foundation for child life specialists to further identify and create developmentally appropriate interventions to decrease the “noise” of common communication barriers within the transactional model, and continue to offer support for patients and families. Dissemination of these findings, through conference presentations and publication, might help encourage child life specialists to brainstorm, address the issue of effective communication, and conduct in further research. The CCLS’ educational background and psychosocial beliefs can benefit the medical team and research findings should be applied to further increase patient satisfaction and provide family-centered care overall.

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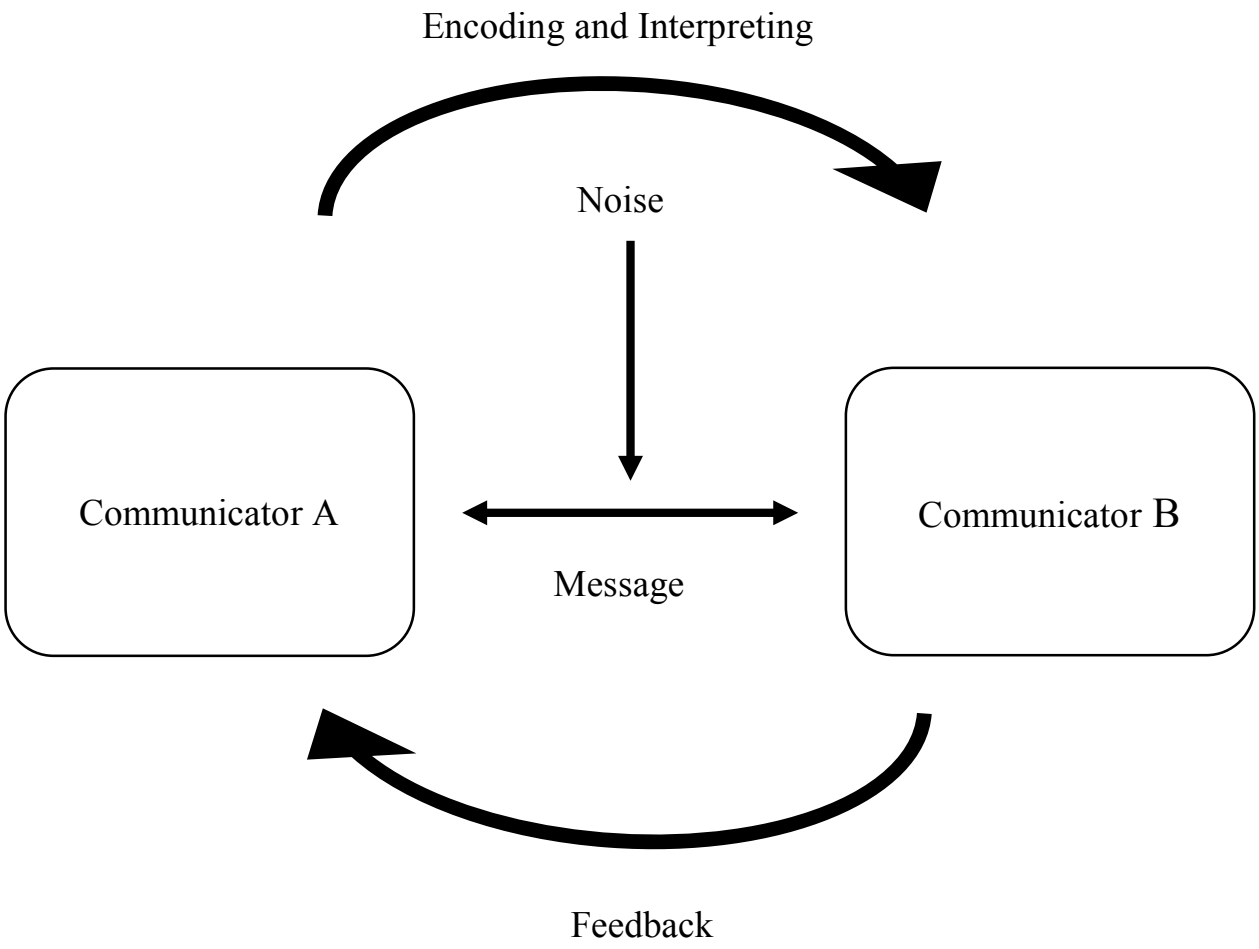
Appendix A

The Transactional Model of Communication



Appendix B

Hello to Whom It May Concern,

My name is Kendall Malkin and I am a certified child life specialist (CCLS), and also a graduate student at the University of Missouri with the hopes of attaining a Masters in Child Life. For my thesis, I chose to survey current CCLS to learn about their relationships with patients and families with any communication barriers in a pediatric healthcare setting.

At least one CCLS from your child life program is requested to fill out this survey. Your responses are highly valued; your participation in this study will help us to identify child life perspectives that will add to the existing literature, and assist in the development of interventions to reduce communication barriers in a medical setting. We greatly appreciate your consideration to participate in our study.

The survey has been approved by the University of Missouri Institutional Review Board. It is expected to take less than 10 minutes to complete. All of your responses are anonymous. Please click the following link to go to the survey. Survey link: https://missouri.qualtrics.com/jfe/form/SV_26nqz7kC5MPRVVH

Thank you and please feel free to pass along to your staff and colleagues. If you have any questions, please contact Kendall Malkin at krm6w7@mail.missouri.edu.

Appendix C

You are invited to participate in a research study, entitled "Healthcare Communication Barriers Encountered by Child Life Specialists." If you have any questions, please contact Kendall Malkin at krm6w7@mail.missouri.edu.

The purpose of this study is to better understand certified child life specialists' (CCLS) perspectives on healthcare communication barriers within their relationships with patients and families in a pediatric healthcare setting. If you agree to participate, you will complete a survey consisting of 20 questions. The survey is expected to take less than 10 minutes to complete. You can decline to answer any questions or quit anytime during the survey. The survey has mobile compatibility if you prefer to complete it on your phone rather than your computer.

The survey is confidential. There are no known risks or costs for participating in this study. Your participation in this survey is voluntary. Your participation in the survey will contribute to a better understanding of ways to reduce communication barriers in the medical setting.

You may be invited for a follow-up interview via email. You have the option to decline to participate in this interview portion. Your answers will be kept confidential.

Statement of Consent: I have read the above information and have had any questions answered. I affirm that I am 18 years of age or older. I consent to participate in the study on child life perspectives on healthcare communication barriers in the pediatric medical setting. **By clicking the arrow button, I indicate my agreement to participate in this study.**

Appendix D

Please fill out the following information in regards to your position as a certified child life specialist (CCLS). Your answers will be kept confidential.

Hospital/Healthcare Setting Name

_____

Location (Town, State)

_____

How many year(s) have you worked as a certified child life specialist?

▼ Less Than 1 (1) ... Over 50 years (59)

We realize that many child life specialists work in more than one area. Which of these areas would you say you spend a *majority* of your time in your work as a child life specialist?

- ○ Inpatient Acute Care (1)
- ○ Inpatient Critical Care (2)
- ○ Radiology (3)
- ○ Pre-surgery (4)
- ○ Outpatient Ambulatory (excluding radiology and pre-surgery) (5)
- ○ Outpatient Emergency (6)
- ○ Other (7)

Which of these patients would you say you work with the most?

- ○ Infants/Toddlers (1)
- ○ Preschool Children (2)
- ○ School-age Children (3)
- ○ Adolescents (4)

To what extent are the following factors barriers to your ability to have high-quality discussions with patients and families in your work as a child life specialist?

	Not a Barrier (1)	Minimal Barrier (2)	Moderate Barrier (3)	Extreme Barrier (4)
Lack of time (1)	○	○	○	○
Inadequate training (2)	○	○	○	○
Lack of long-term relationship with patients (3)	○	○	○	○

Frequent handoffs between child life specialists (4)	○	○	○	○
Lack of clarity about child life specialists' role in these discussions (5)	○	○	○	○
Negative reactions from patients and families (6)	○	○	○	○
Differences in culture among patients/families and child life specialists (7)	○	○	○	○
Language barriers between patients/families and child life specialists (8)	○	○	○	○
Emotional toll of goals of care discussions (9)	○	○	○	○
Unrealistic expectations about care from other healthcare team members (10)	○	○	○	○
Difficulty finding prior goals of care discussion details in the medical record (11)	○	○	○	○
Lack of support from hospital leadership (12)	○	○	○	○

Can you think of additional barriers not listed above?

Please give an example of a past interaction where you experienced a communication barrier with patients and families?

What was the communication barrier(s) you experienced?

Did you seek to reduce this communication barrier in the past interaction you experienced?

- ○ Yes (1)
- ○ No (2)

If you answered "yes," how did you try to reduce this communication barrier?

If you answered "no," please explain why.

Did your approach make the interaction better or worse working with the patient and family?

- ○ Much better (1)
- ○ Somewhat better (2)
- ○ Neither better nor worse (3)
- ○ Somewhat worse (4)
- ○ Much worse (5)

Would you recommend the same approach to another child life specialist?

- ○ Yes (1)
- ○ No (2)

We hope to interview ten certified child life specialists in a follow-up interview. If you would be willing to participate in this interview portion of the study, please fill out the following information in the possibility of being contacted. Your answers will still be kept confidential.

- ○ I decline (1)

First and Last Name

_____

What is an email address or phone number to reach you in case of a follow-up interview?

_____

Appendix E

This interview session will take less than 10 minutes of your time.

1. Based on your answer about this situation interacting with a patient and family, can you explain more about what the communication barrier was and what happened?
2. How did you feel before, during, and after this situation occurred?
3. You took a certain approach with the patient and family. Would you take this approach again?
4. Has a similar situation like this occurred before? If so, how often?
5. Based on your answer (the interviewee's answer will be read back to them from the survey), what would be your advice for another child life specialist in a similar situation, and why?

Prompts were included with the questions based on the interviewee's specific responses from the survey to clarify details of what they had answered about the situation or further determine how the interviewee approached the communication barrier.