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A Call for Self-Examination

Kathryn Cantrell, PhD, CCLS

Since the first issue of *The Journal of Child Life* was published in March, 2020, a global pandemic has changed the way child life professionals work, and the murder of George Floyd has changed the way we advocate against police brutality and systemic racism. This latter event has led our community to question how child life practices perpetuate systemic racism. Editors of *The Journal of Child Life* are seeing this reflected in submissions as more authors investigate topics of diversity, equity, and inclusion, and call for critical self-examination.

You can see a slice of the conversation in this issue. To begin, we include ACLP’s Condemnation of Racism and Discrimination, as well as ACLP’s Commitment to Diversity, Equity, and Inclusion (DEI). In ACLP’s Condemnation of Racism and Discrimination, Lipsey, Kasten, and Stephens call for the community to tune in, listen up, and engage one another in thought-provoking discussions that will expand our sense of self, patient care, and purpose. They suggest prompts for advancing these discussions including an inward look at the trends in child life that perpetuate a state of homogeneity in race, age range, gender expression, thought, educational track, sexual orientation, and religion. In “Disrupting the Status Quo: A New Theoretical Vision for the Child Life Profession,” Koller and Wheelwright offer a strong model for a response. In their theoretical analysis, the authors advocate for child life professionals to critically examine traditional theoretical orientations that can perpetuate racism and lead to a homogenous profession. As they mention, “the time to begin the necessary work of professional self-examination is long overdue.” We hope to see similar examples of critical analysis in future issues.

We also hope *The Journal of Child Life* can be a resource for innovative methods of self-examination. ACLP’s Commitment to Diversity, Equity, and Inclusion offers a helpful guide for child life professionals needing tangible action steps. One recommendation is for clinical staff to create an annual staff competency that focuses on DEI-related, self-reflective practices. In “Assessing the Culture of Diversity among Child Life Professionals at a Midwestern Children's Hospital,” Vermeulen provides an example of an equity audit that could inspire new ideas for assessing the DEI culture amongst your team. Specific examples of how you and your team are addressing racism and discrimination support the entire community’s response, and we look forward to seeing more.

As I mentioned in the first issue, child life professionals are natural investigators and engaging scientifically in self-examination is one of our field’s emerging strengths. The conversations in this and future issues of *The Journal of Child Life* add to an ongoing dialogue that can result in real, systemic change for the patients and families we serve. Consider contributing as you read along.
ACLP’s Condemnation of Racism and Discrimination

Jennifer Lipsey, Chief Executive Officer, ACLP
Bailey Kasten, Chief Operating Officer, ACLP
Kim Stephens, ACLP President on behalf of the ACLP Board

Originally published online on June 2, 2020.

Our hearts are filled with sorrow, anger, and pain as violence and trauma again invade our communities and threaten the lives of our neighbors. The events across the country from this past week have been traumatic and painful for so many people. We have seen evidence of racism and discrimination that continues to cause harm to so many, including our own members and the children and families we serve. ACLP condemns racism and discrimination of all forms.

We join together in grieving and amplify the call for effective and sustainable change within ourselves, our community, and the public at large. We know that racism and discrimination can have long-term impacts on mental health. Racial discrimination is also recognized as a key social determinant of health and a driver of racial and ethnic health inequities. “Racism harms children’s health, starting from before they are born,” said AAP President Sally Goza, MD, FAAP. “A growing body of research supports this, and we cannot ignore the impact.”

As child life professionals, our Child Life Code of Ethics, Principle 3, states that we “are called to ensure that all in our clinical care and with whom we work are not the subject of racism or discrimination.” We must uphold this standard by advocating for systemic change in our workplaces and communities to overcome the policies and practices that continue to harm and traumatize our patients, families, colleagues, communities, and selves.

No one ever said being a child life specialist was easy. We will not be taking the easy way out of this either. We will not ignore, we will not look away, we will not quietly go about our business. We will tune in, listen up, and engage one another in thought-provoking discussions that will advance our sense of self, patient care, and purpose. And we will put those words into action.

In addition to adding our voices and advocacy to the larger efforts within our broader communities, let’s also look inward to identify the various mechanisms in place within the child life community that preserve a state of homogeneity in race, age range, gender, thought, educational track, sexual orientation, and religion, and a restrictive prescription of how to become a successful child life specialist.

If you have lived experience, content expertise, thoughts, or insights that can further shed light on systemic racism and its impacts on you, your peers, patients, and families, then we need you to be a thought leader, writer, social ambassador, or presenter. If you’ve ever been marginalized or identify as a minority and care to share your experience and how it informs your professional evolution, we want you as a content creator, leader, and catalyst as well.

Social injustices like racism aren’t someone else’s problem. These are our problems to face, as your ACLP Board, ACLP staff, and ACLP volunteers. They are your problems to face as well. Standing together, we can galvanize our collective pain and experience into lasting change.
ACLP’s Commitment to Diversity, Equity, and Inclusion

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As a follow up to ACLP’s recent statement condemning racism and discrimination, here are more specific ways in which ACLP will uphold its commitment to Diversity, Equity, and Inclusion (DEI), followed by steps you can take.

ACLP’S Action Steps/Opportunities

1. We will actively seek out and engage minority students with the express purpose of increasing minority recruitment into the pathway to the profession.

2. We will expand the scope of standardized reading materials for child life academic preparation to include DEI content and a diverse array of authors, specifically authors of color.

3. We will require the use of these materials as a standard for academic program endorsement.

4. We will require that all academic programs applying for endorsement show proof of their institution’s comprehensive antidiscrimination policies.

5. We will provide educational content on DEI for practicum and internship students and encourage all institutions offering child life practicums/internships to utilize this content.

6. We will make the content available free to child life practicum/internship students whose institutions do not teach the material.

7. We will make inclusion of this educational material a requirement for internship accreditation.

8. We will require that all clinical programs applying for internship accreditation show proof of their institution’s comprehensive antidiscrimination policies.

9. We will continue to offer diversity scholarships to financially support minority students on their pathway to the profession.

10. We will formally ask the CLCC to include DEI topics in the next job analysis for the purpose of incorporating questions on DEI content on the certification exam.

11. We will ensure that our lineup of webinars and our annual conference include educational opportunities on DEI topics at both the introductory and advanced levels.

12. We will welcome colleagues from other health care professions, as well as members of the public, to engage in these educational opportunities and will ensure that our organization offers a membership category available to health care professionals and public members that includes discounts on educational webinars and conference registration.

13. We will continue to offer affinity groups for our minority members to increase support, growth, and retention in the profession.

14. We will ensure DEI remains an ongoing area of urgent focus throughout our organization by reserving time on the agenda at every board and staff meeting, as well as volunteer committee and task force meetings, for the discussion of DEI efforts and their impact on the groups’ goals and work.

15. We will hold ourselves accountable to the commitments we make here in writing by reporting to our members on the progress of these efforts through town hall meetings, annual reports, articles in the ACLP Bulletin, and discussion at our annual meeting.

Personal Action Steps/Opportunities

Personal work:

1. Read. Solid activism requires personal reflection, insight, and awareness. You are responsible for seeking knowledge through insight and reflection. Use this Guide to Allyship, an evolving, open-source document, and this reading list to get started. ACLP will be beginning a monthly book club for members, starting in August with Heavy by Kiese Laymon.
2. Attend a workshop such as Undoing Racism to deepen self-awareness and insight as a way to continue increasing your racial consciousness.

3. Watch. These posts are small, easily digestible pieces designed to help you understand systemic racism, why blacklivesmatter vs. alllivesmatter, and White privilege.

4. Follow change catalysts on social media to keep up with relevant content and news as it becomes available. Great starting points are @theConsciousKid, @DrRayMD, Michelle Kim, and Child Life on Call: Antiracism and Discrimination Resources for Child Life. The next step is to follow who those change agents are following in order to further expand your worldview and access to change catalysts.

5. Listen. Listen to others and your own (external and internal) voice. What comes up for you when you listen to what others say? What makes you feel defensive, guilty, proud, comfortable, or uncomfortable? Dig in to understand and reflect on the sources of those reactions and how they may be caused by implicit bias and systemic racism.

6. Share. Share openly and be ready to receive feedback, encouragement, questions, or push back. Appreciate feedback and embrace the defensiveness that may arise within as a signal that additional work needs to be done to understand why you reacted in a certain way.

7. Do not expect to check off a list of actions and then consider your work done. Changing years of systemic racism requires internalization of the history, values, principles, and context for its existence. Systemic racism does not go away because individuals donate to causes or like social media posts, although those actions do help. True change requires lifelong learning, patience, compassion, and endurance and all of us working as a collective whole to instigate change.

Supplement your education and self-reflection with actions:

1. Donate to organizations supporting DEI and antiracism work, such as:
   - NAACP
   - Southern Poverty Law Center
   - United Negro College Fund
   - Black Lives Matter

2. Take an implicit bias test, but understand it is not a perfect tool. Use the knowledge gained to create additional learning opportunities and to change practices and behaviors.

3. Talk with your children about systemic racism and White privilege or start by reading a book with them (www.eyeseeeme.com is a great place to look).

4. Advocate. Write to your community, academic, and political decision makers to request what their action steps are for acting on their promise of change.

5. Vote. If you do not feel heard or supported by leaders, use your power to vote to create change.

**Action Steps/Opportunities for Academic Faculties**

**Faculty specific:**

1. Ensure curriculum includes DEI both as a specific area of academic focus and as an integral topic throughout all subjects.

2. Ensure reading lists (textbooks, research, and supplemental books) include authors of color.

3. Ensure simulation modules and case studies include actionable steps to address discrimination in health care settings, implicit bias, and prejudice.

4. Ensure curriculum includes reflective practice allowing students to learn ways to identify how their own race, culture, gender, and sexual orientation influence and impact clinical work.

5. Share information regarding child life academic programs with high school career counselors with intentional focus on schools with diverse populations.

6. Evaluate the student body composition within your program.
Action Steps/Opportunities for Clinical Sites

Staff specific:

1. Create discussions and professional development opportunities related to DEI:
   - Organize/facilitate monthly/quarterly book reviews and discussion groups with staff.
   - Encourage staff to engage in ACLP Affinity groups as appropriate.
   - Provide access to ACLP educational webinars on DEI topics.

2. Create an annual staff competency that focuses on DEI-related self-reflective practices. (Program leaders should actively and intentionally engage in ongoing discussions with staff on DEI focus.)

3. Ensure all department policies are aligned with DEI values.

4. Ensure recruiting and hiring practices are fair and equitable to all.

5. Intentionally and actively recruit minority candidates for practicums, internships, and employment opportunities.

6. Ensure a robust array of resources and play materials that represent children and youth of all races, cultures, orientations, and abilities.

7. Actively seek and engage in opportunities for staff to present information on the child life profession at community and school career fairs in minority neighborhoods and at schools with significant minority populations. Anchor these recruiting efforts with individual follow up and mentorship for minority students as they begin their pathway to the profession.

Clinical training program specific:

1. Advertise your desire to recruit minority candidates for practicums and internships on your website and other PR materials.

2. Require virtual interviews be offered as an option for practicum and internship candidates. Ensure that virtual interviews are weighted equally with in-person interviews when selecting candidates. Consider eliminating in-person interviews altogether.

3. When presented with qualified candidates in excess of your available slots, prioritize selection of minority students.

4. Remove student fees for practicum and internship applications and placements. Use unofficial transcripts only during the application process. If your institution requires official transcripts, request them from students only after they have been offered, and have accepted, a student placement with your institution.

5. Create a scholarship fund to provide financial assistance to minority students during internship.
Group Medical Play and Children’s Self-Reported Fear in the Pre-Operative Setting

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ABSTRACT

Previous research has demonstrated that medical play intervention is associated with decreased pain, fear, and anxiety in children undergoing surgical procedures; however, these studies have typically examined one-on-one, adult-directed, and preparation-focused uses of medical play. Therefore, the purpose of this mixed-methods pilot study was to examine the impact of a group medical play intervention on children’s self-reported fear and observed anxiety in the pre-operative waiting area, and determine the feasibility of group medical play as a research intervention while balancing clinical care. Twenty children (ages 5 to 10 years) scheduled for a sedated surgical or medical procedure in the pre-operative services waiting area of a children’s hospital in the Southeastern United States participated in a 30-minute group medical play session facilitated by a Certified Child Life Specialist. At the conclusion of the group activity, participants used a pictorial scale to rate their level of fear about surgery at two distinct timepoints: prior to and after the medical play session. In addition, they responded to three open-ended prompts about their perceptions of the activity. Participant fear ratings were analyzed using a two-tailed, paired samples t-test, revealing that the group medical play activity was associated with a statistically significant decrease in participant fears about surgery. In conclusion, group medical play as a research intervention was both clinically feasible and effective in reducing children’s fears about surgery, highlighting the value of group play opportunities for children’s coping in health care settings.

Play is essential for the developing child’s cognitive, social, emotional, and physical understanding of the world around them. Moreover, play allows for exploration, self-expression, problem solving, and creativity (Brown et al., 2017). Thus, play is considered to be a cornerstone of the child life profession. Child life specialists capitalize on the power of play opportunities and interventions in generating treatment plans that decrease fear, build rapport, and relieve stress (Cox, 2017). Facilitated play opportunities with an item or person related to the child’s identified health care stressors (e.g., unfamiliar medical equipment, environment, or health care staff) has been found to reduce anxiety, increase coping, and elicit feelings of relief (Nabors et al., 2013). When a child is scheduled for a surgical procedure requiring general anesthesia, unfamiliar medical equipment, separation from caregivers, and anesthesia induction are just a few of the
many unknowns that children will need to process in order to cope with this potentially stressful encounter. However, play provides a language that is universal and intelligible to children, and provides the materials and confidence that they need to express themselves and advocate for their unique coping needs.

One specific mode of play incorporated into the work of a Certified Child Life Specialist is medical play. A distinct concept within the spectrum of play, medical play engages children in play with medical themes and/or equipment in a nonthreatening manner. Medical play is identifiable by four components: (1) it has a medical theme and/or uses medical equipment, (2) it can be adult initiated but must be child directed and maintained, (3) it is playful in nature and often accompanied by laughter and relaxation, and (4) it offers mastery and control over frightening medical environments (McCue, 1988; Turner & Dempsey, 2017). Medical play provides an opportunity for normalization of medical experiences, allows for common misconceptions to be dispelled, and creates an opportunity for a child to be in control, ultimately promoting autonomy and mastery over a situation (Bolig, 2018; Jones, 2018; Williams et al., 2019). These benefits can lead to decreased anxiety and stress throughout hospitalization (Jones, 2018; Williams et al., 2019).

Intentionally exploring and playing with medical equipment (e.g., masks, gloves, syringes, and stethoscopes) is an important component of children’s coping in health care settings. Combining recognizable play methods (e.g., non-scripted and intrinsically motivated play) and unfamiliar medical equipment allows children the opportunity to integrate their thoughts and feelings regarding the situation (Bolig, 2018; Jones, 2018). For example, children’s play with medical toys, such as the playful use of syringes for painting or spraying a stress target, is an effective mechanism for working through the stress related to their health care experiences (Nabors et al., 2013). Simultaneously, medical play can be a vehicle for self-expression, providing children with the opportunity to express their feelings and facilitate positive coping strategies (Nabors et al., 2013).

Although past studies highlight the benefits of medical play within a pre-operative setting, these studies have only included one-on-one medical play sessions provided in the days leading up to surgery, rather than the day of scheduled surgical intervention (Moore et al., 2015). Although one comprehensive review of the literature supporting medical play in the hospital setting has been conducted, health care systems and medical play practices have changed greatly in the 35 years since its publication (Ellerton et al., 1985). Today, there remains a dearth of literature examining the value of same-day, child-directed, group medical play for children undergoing surgery.

Observational studies incorporating medical play have been utilized to identify a child’s prior understanding and new knowledge of their health condition (Dempsey, 2015). However, evaluation of a medical play intervention provided by a Certified Child Life Specialist could offer additional insight and a better understanding of how a child’s stress or anxiety may increase or decrease within the hospital setting, based on participation in a medical play session. Thus, the purpose of this mixed-methods pilot study was to explore the impact of a group medical play intervention on children’s observed anxiety and self-reported fear, while considering the feasibility of offering this intervention in addition to typical clinical child life care. The following research questions were addressed:

1. How do young children in the pre-operative waiting area experience a group medical play intervention facilitated by a Certified Child Life Specialist?

2. What is the feasibility of offering group medical play as a clinical or research intervention in the pre-operative setting?

**Method**

This pilot study was conducted at a children’s hospital within an academic medical center in the Southeastern United States. The site’s surgery department serves approximately 90 to 100 patients per day with a diverse range of diagnoses and surgical needs. Due to the heavy patient volume and high psychosocial acuities in this setting, two full-time Certified Child Life Specialists provide coverage to pre-operative services Monday through Friday from 6:00 a.m. to 3:30 p.m. The site was chosen for the study due to ease of access and the perceived relevance of a group medical play intervention for this population. Institutional Review Board approval for this study was obtained from the research site.
Participants
Participants included 20 children (n = 11 male, n = 9 female) ages 5 to 10 years (M = 7.1) awaiting a sedated surgical or medical procedure in the pre-operative services waiting area. On average, participants had previously undergone 3.5 surgical procedures (range = 0-13). During days of recruitment, participants were scheduled to undergo a range of surgeries or procedures, including dental (n = 3), eye (n = 3), ear, nose, and throat (n = 4), gastrointestinal (n = 4), cardiac (n = 3), or other (n = 5). Of the 20 children in this study, 15 identified as White (75%), three as Asian (15%), one as Black (5%), and one as Hispanic (5%). All participants spoke English as their primary language, presented as typically-developing (no observable cognitive or linguistic disabilities that would preclude participation in a child-directed group medical play activity), and were accompanied by a caregiver over the age of 18 willing to give consent.

Participants were not stratified by surgical type, estimated length of stay, or acuity of procedure; eligible participants were recruited two days per week, totaling 23 days, due to availability of study staff and counterbalancing of clinical service needs. At times, depending upon participant availability, play sessions consisted of one-on-one interactions with the Certified Child Life Specialists. However, of the 20 participants, 12 (60%) engaged in group play consisting of more than one participant.

Eligible participants were identified in the pre-operative waiting area by a trained, graduate-level research assistant. Primary caregivers were approached after completing registration for their child’s procedure. Information about the study was provided by the research assistant, and both parental consent and child assent were obtained via a REDCap survey application on an electronic tablet. Of the families approached, only two declined to participate. One parent stated that they felt they would not have time to participate, and the other parent reported that his son was only having a minor procedure so he felt the intervention would not be necessary. For both situations, the research assistant clarified that the intervention could be stopped at any time and could be beneficial even for minor procedures. However, as participation was completely voluntary, the research assistant did not attempt to persuade the families further.

Procedures
After completing the consent form, the child was accompanied to a child-sized play table in a designated corner of the pre-operative waiting room. Participants who had completed consent and assent forms were given a color-coded sticker to wear, demarcating their participation to the study staff at the table. Parents could choose to watch from seating nearby if preferred; siblings were invited to participate in the intervention as well, but no data was collected on their experiences in this study. Once the participant joined in the activity, the trained research assistant administered a tablet-based demographic survey to the child’s parent; the survey asked caregivers to identify the child’s date of birth, gender, race, ethnicity, reason for surgery, and number of previous surgical procedures, if applicable.

Group Medical Play Intervention
As the child approached the medical play intervention table, they were greeted by a Certified Child Life Specialist who was a trained member of the research team. The Certified Child Life Specialist introduced the activity and supplies and invited the child to observe or join in, depending on their comfort level. As the child approached the table and began to observe the play, another member of the research team assessed the level of pre-operative anxiety at that moment in time using the modified-Yale Preoperative Anxiety Scale (m-YPAS; Kain et al., 1997). For this pilot study, only an overall pre-operative anxiety level was measured.

To initiate the child-directed, group medical play intervention, a Certified Child Life Specialist offered participants their choice of materials, including a blank cloth doll, patient puppet, and stethoscope. Participants were invited to join the play activity using the following script:

*Hi my name is--- . Welcome to the medical play table, would you like to be a doctor or a nurse today? Would you like to check on the patient puppet or make your own patient using this cloth doll and markers?

[child life specialist picks up the stethoscope and asks] Have you seen one of these before?

[pausing and allowing the child to respond] You can handle any of the supplies on the table. I am here to help you.*
One Certified Child Life Specialist provided a supportive presence at the table while completing behavioral observations of the participants as they played.

The other Certified Child Life Specialist took the lead in facilitating the group medical play intervention, following children's cues throughout the activity to support both unstructured and structured play needs. The facilitating Certified Child Life Specialist would enter the play at times with an open-ended question or using reflective language for clarification of play and insights on the child's thoughts. This Certified Child Life Specialist also facilitated the invitation of other children to join in the group and engage in play with their peers, introducing the participants to one another and prompting social interactions during play. At the end of the child's play engagement or at the end of the 30-minute play session (whichever came first), a member of the research team asked the child to answer three open-ended interview questions about the play session and to indicate their fears about surgery (prior to and after the medical play intervention) using a 5-point pictorial fear assessment scale.

**Measures**

**Modified-Yale Preoperative Anxiety Scale (Kain et al., 1997)**

One of the members of the research team rated the child's overall anxiety throughout the group medical play intervention using the m-YPAS (Kain et al., 1997; see Appendix A). The m-YPAS assesses pre-operative behaviors of children that may be indicative of anxiety at a particular period in time, rather than a more generalized state of anxiety that can persist across times and events. The five m-YPAS items are labeled “Activity,” “Emotional Expressivity,” “State of Apparent Arousal,” “Use of Parents,” and “Vocalizations.” Ratings on each item are made on a 4-point scale, except for “Vocalizations,” which is rated on a 6-point scale. For example, a child scoring 1 in “Vocalizations” indicates the child is “reading, asking questions, making comments or babbling, laughing, readily answers questions but may be generally quiet,” whereas a score of 6 would refer to “crying, screaming loudly, sustained.” To form an overall score of the child's pre-operative anxiety, the sum of the ratings across each of the five dimensions were tallied.

**Pictorial Fear Assessment**

This two-question pictorial scale created by the research team (see Appendix B) was used to assess the child's self-reported fear. At the conclusion of the group activity, children were asked to think back to how they felt prior to the medical play session, as well as describe feelings following the play session. The items are labeled “Very afraid,” “A little afraid,” “Not sure,” “Not afraid,” and “Happy.” Ratings are made up of a 5-point scale representing each face (1 = happy, 5 = very afraid).

**Brief Participant Questionnaire**

At the conclusion of the participant's medical play engagement, a research team member asked the child to answer three open-ended questions:

1. What did you think about getting to play doctor with us today?
2. How do you feel about having a surgery/procedure today?
3. What would other kids who are having surgery think about playing doctor with us?

**Results**

The purpose of the study was to assess how young children in the pre-operative waiting area experienced a group medical play intervention facilitated by a Certified Child Life Specialist and to consider whether offering group medical play as a clinical or research intervention in this context is feasible within the bounds of typical child life staffing. To address these questions, both quantitative (descriptive statistics) and qualitative (content analysis) strategies were used.

**Length of Play Participation**

Average time played, average m-YPAS ratings, and changes in child-reported fear questions were analyzed using Microsoft Excel. Play time was measured from the time the child approached the table to the time at which they completed play engagement (either by choice or by being called to the holding room). Depending on the child's interest level and surgery or procedure start time, participants engaged in the intervention anywhere from five to 30 minutes. On average, participants played for 16 minutes.

**Observed Anxiety and Self-reported Fear**

Within the parameters of the m-YPAS, scores can range from as low as 5 points (minimal distress) and as high as 22 points (maximum distress). While participating in the group medical play intervention, participants demonstrated an average m-YPAS score
of 5.65 that reflected their overall anxiety from start to finish, meaning that children showed relatively low levels of pre-operative anxiety throughout the medical play interaction. When asked to report their feelings of fear about their surgery or procedure prior to and after the medical play intervention, a paired sample t-test demonstrated significant decrease in fear (p ≤ .05) after engaging in the group medical play activity. Specifically, children reported an average fear rating of 2.35 prior to the intervention and an average of 1.7 after playing doctor (happy = 1, very afraid = 5).

**Qualitative Findings**

Participant responses to the three open-ended prompts were analyzed using content analysis (Hsieh & Shannon, 2005). Content analysis is a methodology in which researchers examine qualitative data to identify common categories and themes that characterize responses. In this study, content analysis involved two members of the research team independently reading through all of participants’ responses to open-ended questions about their play experiences. Given the brief nature of these responses, these team members were able to quickly identify commonalities without discrepancy.

Overall, 90% of participants reported positive feelings about their medical play experience, stating that they felt “playing doctor” was “fun,” “good,” “happy,” or “I liked it.” In the words of one participant, “I liked it, I really liked it.” Participants also reported that they felt other children having surgery would also “enjoy” “have fun,” or “feel good” about the group medical play intervention. Only two participants reported that they either did not know how they felt or felt “just okay” when engaging in the activity. These two particular responses could be due to a variety of external influences, such as a hurried transition to the holding room or competing environmental stimuli in the busy pre-operative waiting area. When participants were asked how they felt about their scheduled surgery that day, 40% reported feeling positive by either responding, “good” or “happy.” One participant shared, “I feel good, I’m ready for it.” The rest of the participants stated feeling either “a little scared,” “sad,” or “bad about having surgery” (30%) or “unsure” about how they felt (30%).

**Feasibility**

The research team, through consensus discussion and efficacy of data collection, found this study and the group medical play intervention to be feasible while also balancing clinical child life care. As the research team was composed entirely of individuals with expertise in child life services, it was possible to design an intervention that explored the use of a foundational child life intervention for evaluative purposes (i.e. evaluating the efficiency and the feasibility of conducting a group medical play session in the pre-operative waiting area). Furthermore, the child life lens shared by team members encouraged reflection not only on the individual participants’ experiences but also aspects of intervention design, group dynamics, and workflow.

In terms of feasibility, the research team identified the importance of staffing the medical play intervention table with two clinicians at a time, which promoted optimal data collection and maximized the balance of group medical play with typical clinical workflow. In this model, one Certified Child Life Specialist facilitated the group play activity and the other served in a data collection role, recording observations and scoring the m-YPAS. This model also proved effective in balancing clinical workflow—when one Certified Child Life Specialist was called away, the other was still able to collect data with the research assistant. In addition, varying participant recruitment techniques and schedules revealed that mid-morning hours (typically between 9:00 a.m. and 11:00 a.m.) on Mondays and Thursdays yielded the largest numbers of eligible participants, likely due to the types of procedures scheduled on these days. Finally, the addition of a research assistant made it possible for parents to complete the demographic survey while their child engaged in the group medical play activity, thereby minimizing burden on the family and maximizing the short wait times experienced in the pre-operative waiting area.

**Additional Findings**

Additional informal observations of the group dynamics and level of engagement in the activity also provided insight into the effects that group medical play can have on a child’s pre-operative distress. While siblings and children who did not meet inclusion criteria for this study were not invited to participate in the study, they were not excluded from the play activity; rather, the addition of siblings and other non-participant children may have broadened the play themes and opportunities available to participants as the group dynamics continually shifted.
In addition, several participants were observed to engage in role play with siblings or caregivers seated nearby, while others utilized peer interaction as an opportunity to share their own medical experiences or ask other children about theirs. These interactions gave depth to the activity and provided children with an opportunity to demonstrate mastery of their own health care experience.

Differences in interest level in the activity, based on age, were also anecdotally observed. Children ages five to eight years were observed to utilize a combination of both real and play medical equipment throughout the activity and typically chose to engage with the patient puppet or create their own blank cloth doll. In contrast, it was noted that several participants ages nine to 10 years gravitated towards engaging solely with the real medical equipment. A lack of interest in the blank cloth dolls and patient puppet appeared to be consistent across this older age group, in line with what would be expected with regards to school-age development.

The information that the children revealed during the intervention became a helpful source of insight to the clinician for future assessment, intervention, and research planning. As the assigned surgery Certified Child Life Specialist collected study data, they gained additional information to inform assessments related to patient care. They were able to predict which children would require additional support once they transitioned to the holding area and then eventually the operating room. Furthermore, these insights were gathered without compromising or disrupting the flow of patient care in the pre-operative waiting area and the interventions initiated as a result of these insights were positively received by patients, families, and pre-operative services staff.

Discussion

The purpose of this study was twofold: first, to examine the impact of a group medical play intervention on children’s self-reported fear and observed anxiety in the pre-operative waiting area, and second, to explore the feasibility of group medical play as a research intervention. The results of the pilot study align with foundational principles of child life practice, namely, the emphasis placed on play as a coping tool for children undergoing stressful health care experiences. The children in this study reported a decrease in fear about surgery or their procedure after engaging in the child-directed group medical play activity, thus reinforcing previous work by Moore and colleagues (2016) and Turner and Dempsey (2017). Group medical play appears to be a promising research intervention alongside its value as a clinical tool for assessing children’s fear and anxiety regarding surgery.

The medical play activity presented in this pilot provided participants with a nonthreatening opportunity to handle, explore, and investigate real and pretend medical equipment to which they may or may not have been exposed before. The format of the intervention appeared to foster a sense of trust and exploration like previous work by Nabors and colleagues (2013); most participants were observed to feel comfortable enough to ask a question about an item they were not familiar with, such as the anesthesia mask. Maintaining a child-directed atmosphere as defined by McCue (1988), the intervention provided the clinician opportunities to enter the play when asked, for example, to provide a description of the equipment or clarification about how it is used. This occurred frequently around the anesthesia mask, with the Certified Child Life Specialist stating, “that is called an anesthesia mask or what some kids call the ‘sleepy air’ mask.” Following the short explanation, play resumed quickly, and children played on. While past studies highlight the use of medical play interventions in the days leading up to surgery (Moore et al., 2015), this study reveals a significant decrease in anxiety when the intervention is implemented on the day of surgery; thus, supporting the design and the effectiveness of the study.

Another outcome of this study was the feasible adaptation of a clinical intervention for the purposes of research. Not only was it feasible to study group medical play for children undergoing surgery, but also to provide clinical care as an intervention for empirical evaluation without sacrificing clinical time or quality of clinical care. Although two Certified Child Life Specialists were needed to conduct this study, they were able to effectively work together to manage concurrent clinical needs, especially with the addition of a trained graduate student previously involved in child life study and research. This study further highlights the importance of collaboration across academic and clinical settings, not only to ensure best practices, but also to provide optimal training for emerging professionals.
Conclusion

The results of this study highlight the feasibility and utility of a group medical play intervention for supporting children awaiting surgical procedures. Through informal feedback and observation, children and parents positively responded to the intervention, and some children’s behavior (e.g., asking age-appropriate questions, recounting events, and sharing personal medical experiences) demonstrated a sense of mastery and control when engaged in the medical play opportunity. Therefore, a group medical play intervention may serve children awaiting a surgical procedure well, even in the busy environment of the pre-operative waiting room, perhaps helping them to prepare for and adjust to their upcoming procedure.

In terms of feasibility, this study revealed opportunities for some logistical modifications and considerations. A longer timeframe for the medical play session could allow for increased participation and peer interaction. Additionally, an assessment utilizing the m-YPAS scale prior to play and at the conclusion of play (in a pre-post-test format) could increase accuracy and effectiveness of data, thus further optimize the intervention. These changes would allow for a greater number of children to participate and an opportunity to explore potential causal links between the group medical play session and children’s fear and anxiety in the pre-operative setting. Further research is needed to better understand the potential impacts of a group medical play intervention, perhaps utilizing a matched control group and additional empirically validated measurement tools to capture anxiety, pain, and other distress-related variables.

References


Appendix A:
Modified-Yale Preoperative Anxiety Scale (Kain et al., 1997)

**Activity (Circle One)**
1. Looking around, curious, playing with toys, reading (or other age-appropriate behavior); moves around waiting room to get toys or go to parent
2. Not exploring or playing, may look down, may fidget with hands or suck thumb (blanket); may sit close to parents while waiting
3. Moving from toy to parent in unfocused manner, non-activity-derived movements; frenetic or frenzied movement or play
4. Actively trying to get away, pushes with feet and arms, may move whole body; in waiting room, running around unfocused, not looking at toys or will not separate from parent

**Vocalizations (Circle One)**
1. Reading, asking questions, making comments or babbling, laughing, readily answers questions but may be generally quiet.
2. Responding to adults but whispers, “baby talk,” only head nodding
3. Quiet, no sounds or responses to adults
4. Whimpering, moaning, groaning, silently crying
5. Crying or may be screaming “no”
6. Crying, screaming loudly, sustained

**Emotional Expressivity (Circle One)**
1. Manifestly happy, smiling, or concentrating on play
2. Neutral, no visible expression on face
3. Worried (sad) to frightened, sad, worried, or tearful eyes
4. Distressed, crying, extreme upset, may have wide eyes

**State of Apparent Arousal (Circle One)**
1. Alert, looks around occasionally, notices/watches staff (could be relaxed)
2. Withdrawn child sitting still and quiet, may be sucking on thumb, or face turned in to adult
3. Vigilant, looking quickly all around, may startle to sounds, eyes wide, body tense
4. Panicked whimpering, may be crying or pushing others away, turns away

**Use of Parents (Circle One)**
1. Busy playing, sitting idle, or engaged in age-appropriate behavior and does not need parent; may interact with parent if parent initiates the interaction
2. Reaches out to parent (approaches parent and speaks to otherwise silent parent), seeks and accepts comfort, may lean against parent
3. Looks to parents quietly, apparently watches actions, does not seek contact or comfort, accepts it if offered or clings to parent
4. Keeps parent at distance or may actively withdraw from parent, may push parent away or desperately clinging to parent and will not let parent go
Appendix B: Post-Intervention Fear Assessment

Pictorial Fear Assessment

1. Which of these faces shows how afraid you felt before we played today?

- Very Afraid
- A little afraid
- Not sure
- Not afraid
- Happy

2. Which of these faces shows how afraid you feel now that we have played together?

- Very Afraid
- A little afraid
- Not sure
- Not afraid
- Happy
Assessing the Culture of Diversity Among Professionals at a Midwestern Children’s Hospital

Amanda Vermeulen, MA, CCLS

ABSTRACT

The ever-changing ethnic and cultural landscape of the United States drives the need to better understand diversity in its workforce. The purpose of this study was to conduct an equity audit in a midwestern children’s hospital's psychosocial department to assess the perceived culture of the diversity climate. The goal of the equity audit was to uncover ways in which the department could identify needs and strengthen awareness towards the development of an inclusive environment. The equity audit was conducted in the form of a questionnaire addressing four main themes identified in workplace diversity research: physical environment, matching, communication, and leadership. Results showed that the culture of diversity appeared to be an optimistic one with many opportunities for growth and change. Overall, the questionnaire proved helpful in assessing the culture of diversity among professionals at the Midwestern children's hospital and identifying opportunities for awareness and inclusion.

The U.S. Census Bureau predicts that minority groups will comprise more than half of the population by 2044 (Colby & Ortman, 2015). Because of the changing ethnic and cultural landscape of the United States, there is a need to understand diversity in the workforce. Diversity itself is a difficult ideology to define; however, in the most basic sense, diversity is the differences of individuals based on positions within the society in which they live (Calasant, 1996). Diversity, according to De Meuse and Hostager (2001), “elicits a range of emotions, thoughts, and behaviors” that individuals bring to an organization (p. 47). Service delivery, like health care, also continues to adapt and change over time. Hospitals and the community environment are interconnected, and the more inclusive the environment, the better the two will work together and thrive (Ragins, et al).

Under the 2010 Affordable Care Act, patient and family satisfaction scores now greatly impact hospitals’ financial support. This movement has resulted in increased attention toward cultural competence, defined as the awareness of one's own world view and the ability to positively interact with people across cultures, in the community and health care environment (Skaggs & Knec, 2012). Whitman and Valpuesta (2010) found that the more diverse the workforce, the more likely staff are to understand multiple cultures, respond to differences, and provide quality care. Thus, it is important to identify supports and processes that assess cultural competence in the work environment (Pearson et al., 2007).

One way to assess an environment’s cultural awareness is by conducting an equity audit. Equity audits, in the form of questionnaires, document reviews, and interviews, have become increasingly valuable to health care organizations. Some organizations use data from audits to aid in decision making on behalf of the healthcare environment and community (Weech-Maldonado et al., 2012). Matthews (1998) used a diversity audit to identify organizational problems, create strategic plans, compare practices, and to prioritize pluralistic initiatives. Because hospitals are complex organizations and melting-pots of the local environment, staff should be aware of diversity and practice competence when delivering care.

The purpose of this study was to conduct a pilot equity audit in a midwestern children’s hospital’s psychosocial department to assess the perceived culture
(behaviors, beliefs, and values) of diversity within the environment. The goal of the equity audit was to uncover ways in which the department could identify needs and strengthen awareness towards cultural competency. It is important to note that diversity and culture can be challenging to define due to varying contexts. For this study, the definition of culture, typically defined as the customs, arts, social institutions, and achievements of a nation, people, or social group, was left open to interpretation. However, the terms diversity, different groups, and range of backgrounds were defined to include diversity based on ethnicity, language, income, physical ability, mental ability, gender, and religion.

The current study outlines definitions of diversity and themes related to diversity in the workplace as synthesized from an extensive literature review. Themes include the physical environment, matching, communication, leadership, and education. The study describes the steps of completing an equity audit and concludes with results and application of information collected from the equity audit.

**Literature Review**

Researchers have expanded understanding of the impact of diversity in the workforce by assessing hospitals, organizations, human resources departments, individual workers, and communities. When defining diversity, previous researchers sought to consider diversity beyond the commonly-identified phenomena, race and gender, to also include psychosocial differences, generational differences, and social constructs. Weech-Maldonado and colleagues (2012) suggested the definition should also include health literacy, sexual orientation, and mental health. Groggins and Ryan (2013) considered diversity as any differences between people or groups and stated that the diversity climate includes perceptions of organizational characteristics and individual values. However, Marques (2010) preferred a unique holistic approach to defining diversity in stating “we are all members of the human species, thus not really significantly diverse” (p. 436).

Multiple research approaches and methods have been used in health care- and diversity-related research, but similar findings have emerged in relation to providing optimal care and demonstrating cultural competence. Benefits to businesses that value cultural competence, uncovered by the research of Groggins and Ryan (2013), included sales growth, customer satisfaction, positive business outcomes, employee retention, community collaboration, improved communication, reduced ethnic disparities, and openness to change. Along with the many benefits, the findings, or themes, most often identified in research are related to the environment, diversity in the workforce (matching), communication, leadership, and educational training. The diversity-related themes laid a foundation for organizations to understand and respond to diversity so that partnerships could be made with the community and health care system. The following section provides an overview of common themes identified from a multitude of diversity-related studies.

**Physical Environment**

The physical environment of a hospital setting includes not only the building/campus, but also the social spaces, eating venues, sacred places, public areas, visual appearance, resources available, and attitudes of community acceptance. Lambert and colleagues (2013) agreed that the hospital environment can create positive experiences for patients, families, and staff, and can foster connectedness. In their study, children and families agreed that social spaces, like lounges and playrooms, which allowed leisure, entertainment, and connectivity, were most important in creating positive perceptions of an inclusive environment. Social spaces that included elements of integration, sharing, accessibility, socialization, resources, and diversity (ethnic, gender, ability, and interest) were most often identified when asked about feelings of belonging.

Research conducted by Linden and Nyberg (2009) focused on the impact of food consumption in the workplace as an identity marker, discussion topic, and non-verbal cue of ethnic diversity. Their research identified the lunch area as a melting pot for intercultural exchange, food preferences, traditions, and signs of gender, age, marital status, and ethnic origin. Participants in their study felt the lunch room was part of the community- and relationship-building process. Overall, the impact of food consumption in a public arena creates an important awareness for diversity.
Finally, spiritual or sacred places in health care settings are an important, yet sensitive part of the environment. Reimer-Kirkham and colleagues (2012) studied sacred places in health care and recommended that caregiving environments should contain spaces that nurture relationships, depict a variety of symbols, and accommodate multiple perspectives. Individuals in the study wished to continue practicing their spiritual beliefs throughout illness; therefore, a challenge was identified in creating a neutral space that was both culturally appropriate and welcoming to all visitors. Thanks to the research, it can be concluded that the physical environment contributes in many ways to diversity awareness in a pluralistic society.

**Matching**

One way that hospitals achieve cultural competence is through matching, which can be accomplished through recruiting a more diverse workforce. Matching, as described by Whitman and Valpuesta (2010), occurs when the "demographics of the workforce mirror that of the patient population" or community (p. 117). In their research, Skaggs and Kmec (2012) found that the larger the hospital and surrounding community, the more diverse the workforce. Matching in health care has a direct impact on employee desire to live in a specific community, patient compliance with treatment, and collaboration and communication among patients and care providers (Pearson et al., 2007; Polacek & Martinez, 2009; Ragins et al., 2012).

Having a patient-provider cultural match creates a stronger relationship by engendering trust, feelings of inclusion, and equal participation (Polacek & Martinez, 2009; Ragins et al., 2012). McGinnis and Moore (2009) stated that cultural competence develops within an environment that is welcoming to people of color and is one that provides equal opportunities and rewards. Involving minority community groups in the hospital design and services offered can result in a more diverse workforce that can increase the cultural competence and reduce disparities.

**Communication**

Culture and language determine how information is received, understood, and acted upon (Polacek & Martinez, 2009; Whitman & Valpuesta, 2010). Communication can be both a barrier and an avenue toward culturally competent care and satisfactory patient outcomes. There are many complex characteristics of communication mentioned in research that can jeopardize cultural sensitivity including nonverbal cues, volume, word choice, pronunciation, physical touch, written words, and the use of medical jargon (Polacek & Martinez, 2009; White & Chalmers, 2011). Patients and families identify a more positive satisfaction and greater well-being when clear, linguistically relevant, inclusive communication is used (White & Chalmers, 2011; Whitman & Valpuesta, 2010).

Another part of culturally competent communication is access to interpreters and resources in a variety of languages. Research has found that a strong determinant of positive patient experiences is related to on-site access to trained interpreters and having health information that is cognizant of cultural norms and written at an appropriate literacy level (Pearson et al., 2007). It is vital for hospitals to provide frequent evaluations of interpreter services for the safety of patients and to aid in overall communication. White and Chalmers (2011) identified that an easy way to increase effective communication is by documenting language preferences in the patients’ medical records. Groggins and Ryan (2013) found that the more everyone was free to speak their language and openly celebrate their culture the more integrated the team.

**Leadership**

White and Chalmers (2011) emphasized the importance of recognizing the priority and value that leadership places on cultural and linguistic diversity. Leaders can have a great influence over the attitudes and climate of an environment that affect staff and consumers. It is vital for leaders to have system policies in place that can positively impact the level of culturally competent care (Pearson et al., 2007; Polacek & Martinez, 2009; Weech-Maldonado et al., 2012). Studies have found that management plays a key role in modeling cultural competence, and human resource departments can facilitate an ongoing commitment and ensure policy follow-through (Whitman & Valpuesta, 2010). Management that supports a diverse workforce, utilizes accommodation policies, and implements mentor programs encourage greater openness to peer differences (Groggins & Ryan, 2013). Finally, Weech-Maldonado and colleagues (2012) found that continual monitoring and outcome assessment is needed in order to keep pace with the ever-changing staff and patient population.
**Education**

Education is typically part of the process that leads to understanding and demonstrating skills in a new concept, and cultural competence is no exception. In fact, Pearson and colleagues (2007) and White and Chalmers (2011) agreed that diversity is so complex that training should be an ongoing process that starts with developing cultural competence at the undergraduate, postgraduate, and medical school level. Training interviewers to recognize bias is just as important as hiring someone who provides exceptional care (Lumb et al., 2010). Polacek and Martinez (2009) urged that cultural training also be assessed for bias and that the training itself be diverse and representative of the community environment. After extensive research, De Meuse and Hostager (2001) went so far as to say that frequent diversity training may be irrelevant if initial focus is placed on building a strong, caring workforce where similarities are celebrated. Having multiple opportunities for education and assessment can create awareness and initiate improvements toward an inclusive workforce climate.

**Current Study**

The purpose of this study was to conduct a pilot equity audit in a midwestern children's hospital's psychosocial department to assess the perceived culture (behaviors, beliefs, and values) of diversity within the environment. The audit included a variety of assessments related to the common themes found in research including environment, matching, communication, leadership, and education.

**Methods**

**Research Setting**

The study was conducted within a mid-sized children's hospital in the Midwest. The hospital includes 80 inpatient beds, an emergency department, outpatient specialty clinics, a surgical floor, and a radiology/diagnostic center. The hospital serves both rural and urban communities from surrounding states. The hospital was built in the year 2007 and operates under an overarching medical foundation. The hospital was designed with input from staff, a parent advisory board, and previous patients. Staff that work in the children's hospital are specifically trained in pediatrics. The mission statement of the hospital is to work together to be a national leader in health care, advancing the well-being of all people through excellence, innovation, compassion, integrity, respect, and accountability. This study took place over a three-month period with a questionnaire being electronically available for four weeks.

**Participants**

Participants were restricted to a psychosocial department within the children's hospital that consisted of child life specialists, social workers, chaplains, administrative staff, and support staff. Of the 27 individuals invited, 17 voluntarily completed the questionnaire. All but one of the participants were female. All 17 participants were White, ranging in age from 27 to 59 years. The mean age of participants was 40 years old. One participant responded “middle age” and listed no chronological number. Participants most frequently reported having six to 10 years of service at the Midwestern children's hospital (six participants), while all participants ranged between fewer than six months to 21 to 25 years of service.

**Questionnaire**

An email invitation was sent to 27 staff with a description of the research, consent information, and SurveyMonkey link to the questionnaire. The questionnaire was available for a four-week time period during the spring of 2015. One reminder email was sent during the third week to encourage the participation of any other staff who had not already completed the questionnaire. A consent form was included in the email, and participants consented by clicking the SurveyMonkey link to begin the questionnaire.

An equity audit, in the form of a questionnaire, was adapted to fit the Midwestern children's hospital from research by De Meuse and Hostager (2001), Ginsberg (2004), Pearson and colleagues (2007), Weech-Maldonado and colleagues (2012), and Whitman & Valpuesta (2010). The questionnaire (see Appendix A) began with a short section to gather participant demographic information such as sex, age, race, ethnicity, and years of service. The questionnaire contained 21 Likert-style items that asked participants to rate each item according to their experiences within the hospital and department as strongly agree (1), neither agree nor disagree (2), or strongly disagree (3). The questions were divided into sections to more easily organize the data: environment and matching, communication, leadership and diversity education. One open-ended reflection question asked participants to identify one or two of the previous hospital environ-
ment, matching, communication, leadership, or diversity education items that, from their perspective, were most important/critical to diversity within the hospital (see question #22 in Appendix A).

The questionnaire concluded with the Reaction-To-Diversity Inventory (RTDI) developed and validated by De Meuse and Hostager (2001). This tool was designed as a non-threatening assessment of attitudes and perceptions of workplace diversity. The tool was created as a generalized measure in order to create openness and individual interpretation to varying perspectives. The instrument includes 70 one-word items that are both positive and negative. The words are used to assess an optimistic, realist, or pessimistic outlook on a 5-dimensional framework of workforce diversity including categories of emotional reactions, judgments, behavioral reactions, personal consequences, and organizational outcomes. Participants in the current study were asked to check each word that they frequently associated with their present-day workplace diversity (see question #23 in Appendix A).

Data Analysis

Descriptive statistics and measures of central tendency were used to analyze the data. Standard deviations and frequency distributions of Likert scale items were computed. Standard deviations closer to 1.0 indicated that participants had varied opinions, and scores closer to 0 indicated that participants had similar opinions. Two incomplete surveys were eliminated, leaving 17 completed. The open-ended question was coded by categorizing responses based on the established diversity themes and by counting the number of times each theme was identified.

The RTDI was scored by giving each positive word a value of +1 and each negative word a value of -1. The total score was then added for a summary of participants’ overall orientation to workplace diversity. Scores ranging from +35 to +11 were classified as optimists. Scores ranging from +10 to -10 were classified as realists. Scores ranging from -11 to -35 were classified as pessimists.

Results

Questionnaire

The data collected aimed to assess whether participants were in agreement or had varied opinions about hospital diversity-related themes. Most of the participant responses included some degree of varying opinion, indicated by a standard deviation of 0.70. The question in which participants most agreed was related to the role of leadership in-services and training. Of the 17 participants, 14 strongly agreed (82%) that the organization’s leadership should encourage culturally and linguistically diverse services and training. Most participants (76%) also agreed that they felt comfortable discussing diversity issues within their department. Participants differed most regarding their perceptions of the adequacy of the hospital’s interpreter services meeting the needs of patients and families. The question in which the greatest number of participants strongly disagreed (59%) was related to the hospital’s special events.

Open-Ended Question

The open-ended question asking participants to share which of the diversity themes was most important/critical within the hospital was answered by 12 participants. Seven participants agreed that diversity education was most important by stating the desire for “educational classes,” “cliff-notes version of different cultural beliefs and traditions,” and “training.” One participant felt that “yearly reviews or testing” would be helpful to “increase staff awareness.” Six participants stated that communication was most important in relation to “interpreter services,” “resources,” “care provided,” and “face-to-face interactions.” The physical environment, such as a place “that supports and welcomes the diversity of all staff, visitors, and the community” was valued by three participants. Responses such as “leadership making it an everyday practice to provide staff with the information needed” revealed that two participants felt that leadership was most important. Finally, two participants noted that matching was critical in the hospital setting, with one participant mentioning “increasing opportunities for a more diverse patient/family population to be involved with patient education.”

Diversity Inventory

The positive and negative words in the RTDI were organized into five categories: emotional reactions, judgments, behavioral reactions, personal consequences, and organizational outcomes. Overall, the 16 participants who completed the inventory were optimistic about workplace diversity, indicated by a mean score of +23. Out of the 35 positive words presented in the inventory, only two words were not chosen by any of the participants: merit and profitable.
The words, all positive, chosen most by participants included compassionate (12), ethical (10), listen (9), support (8), team-building (7), collaborate (7), and opportunity (7). “Behavioral reactions” was the highest scoring category for positive words with +47 score.

Out of the 35 negative words presented in the inventory, only 10 were chosen by the 16 participants. Participants chose most negative words from the personal consequences category, which included insecurity (3), pressure (1), rivalry (1), sacrifice (1), and stress (2). Other negative words chosen were categorized as emotional reactions: confused (4) and frustration (3); and organizational outcomes: bureaucratic (1), regulations (2), and turnover (3).

Discussion

The purpose of this study was to assess the perceived culture of diversity at a midwestern children's hospital and to identify ways to strengthen awareness of diversity within this hospital. Results from the equity audit provided great insight into the culture of diversity within the Midwestern children's hospital's psychosocial department. Most importantly, participants appeared open to diversity in health care, which was demonstrated by their willingness to complete the questionnaire and by their openness to discussing diversity with others. Staff indicated being generally open to further learning and diversity education and reported a desire to learn more in order to provide better care and service. Overall, the study contributed to understanding the culture of diversity within a children's hospital setting. Specifically, results showed that the culture of diversity appeared to be an optimistic one with many opportunities for growth and change. Groggins and Ryan (2013) suggested that a diversity assessment should be a continuous and ongoing process. The next five sections will look at the current study results as related to the diversity-related research themes.

Physical Environment

Several elements within an environment can affect perceptions of diversity. Elements in a hospital setting that could impact diversity include physical structure, social spaces, eating venues, religious places, public areas, visual appearance, resources available, and attitudes of community acceptance (Lambert et al., 2013; Linden & Nyberg, 2009; Reimer-Kirkham et al., 2012). The current study found that there were differing opinions related to diversity within the environment. More participants agreed that the Midwestern hospital lacked diversity within family spaces, food offerings, and special events. It is important to be aware of the impacts of an environment on overall psychosocial well-being, especially those related to leisure, entertainment (like special events), and social connectivity (Lambert et al., 2013). One participant in the current study stated that “acknowledging events and holidays of other cultures would be important to diversity.” However, participants also felt that the hospital modeled diversity within the artwork, informational displays, and social media and was welcoming overall. All the elements together show that the hospital environment is more than physical space or care provided. As Reimer-Kirkham and colleagues (2012) emphasized, diversity in health care is about creating an experience.

Matching

Research has found that a diverse workforce leads to increased performance, innovation, cooperation, community involvement, and cultural competence (Ragins et al., 2012; Whitman & Valpuesta, 2010). A diverse workforce can often be achieved by matching the demographics of the workforce to the demographics of the community. In the current study, participants agreed that the Midwestern children's hospital matched the diversity of the patient population. One participant stated, “I think this is challenging; 88.9% of people living in this midwestern state are Caucasian. I think the hospital staff is representative of that statistic.” Even though the match of the local workforce may be accurate, there is still a need for culturally competent care in order to avoid health disparities and to diversify the cultural climate (Polacek & Martinez, 2009).

Communication

In their study, White and Chalmers (2011) found that the process of communication within health care lends itself to the biggest challenges, the most complaints, and the greatest complexities. Whitman and Valpuesta (2010) also identified communication as the most important factor in health and well-being. The current study assessed different modes of communication for their promotion of diversity and equity and found diverging opinions. Varied responses were related to interpreter services, resources from diverse perspectives, care to support all backgrounds, and individualized patient education materials. One
participant indicated that the “hands-on or face-to-face interactions” were most important to diversity within the hospital, while another stated “interpreter services” were most critical. It can be concluded that improvements in communication equity need to occur for participants to feel confident and agreeable about services provided.

Previous and current research show that communication encompasses more than spoken or written language. However, communication can also result in the greatest cultural barriers (Polacek & Martinez, 2009). One positive derived from the current study was that none of the participants indicated that they did not feel free to discuss diversity issues within their department. The existence of openness and awareness of diversity leads to increasing acceptance and inclusion, which ultimately develops into respect (Groggins & Ryan, 2013). The fact that participants volunteered time to participate in the questionnaire also shows their openness and willingness to discuss diversity-related issues.

**Leadership**

Much of the previous research exploring diversity in the workforce and within health care found that diversity is greatly influenced by the leadership team. Leaders at all levels can make an impact on employee attitude, policy, the environment, level of care, growth, improvement, and follow-through (Reimer-Kirkham et al., 2012; Weech-Maldonado et al., 2012; Whitman & Valpuesta, 2010). The current study supported previous research finding that participants feel that it is within the role of leadership to recruit staff from diverse backgrounds, ensure the leadership team is diverse, advocate for social justice, and encourage culturally and linguistically diverse services. One participant stated, “Leadership is making it an everyday practice to provide staff with the information needed to provide a patient- and family-centered approach for ALL.” Another participant felt that leadership could increase “staff awareness of the varieties of diversity by education and/or yearly reviews with testing.” One of the greatest lessons learned from the current study is that participants overwhelmingly agree that leadership should be held responsible for diversity matters.

**Education**

Diverse services, according to Groggins and Ryan (2013), would include employee training and education. When asked, participants in the current study most often indicated that diversity education was critical for supporting hospital diversity. Participants valued and desired “educational items and materials,” “educational classes,” “presentations,” “learning materials and strategies,” “training in working with diverse populations,” and “having more educational pamphlets, handouts, and resources.” However, participants were impartial on whether the Midwestern hospital trained support staff and medical personnel to identify and care for patients from different cultural backgrounds. It can be concluded that staff value training and education in order to work toward the most inclusive environment and that leadership can help in creating awareness and implementing positive policies. It is important to remember that because the concept of diversity is so complex, assessment, discussion, and training should be an ongoing process (Groggins & Ryan, 2013; Pearson et al., 2007; White & Chalmers, 2011).

According to the RTDI results, participants were optimistic about workplace diversity overall. It was interesting that the positive words most often chosen were from the behavioral reactions category, which reflects an individual’s planned verbal and nonverbal actions. Participants from the hospital’s psychosocial department have been trained in listening, supporting, and understanding, which could explain why words from the behavioral reactions category were so often chosen. It was also interesting that two positive words not chosen by any participants, “merit” and “profitable,” relate to money. Participants may have viewed these words more negatively or may not have placed a high value on money and, therefore, did not connect money to diversity. Finally, the negative words most often chosen were from the category of personal consequences. Personal consequences, such as “stress” and “insecurity,” relate to perceptions of how diversity might affect everyone (De Meuse & Hostager, 2001). Current participants’ negative feelings may have contributed to a lack of training or education related to diversity.

**Conclusion**

**Limitations**

Some limitations do exist within the current study. First, the sample was not representative of the workforce of the Midwestern children’s hospital; a more representative sample would include all departments
and staff within the hospital. Expanding the research to other disciplines, not just the psychosocial department that is likely to be more open to diversity in general, may provide different results and create a different picture of the culture of diversity. Second, there was one error made in utilizing the RTDI: The word “lashes” was used instead of the word “clashes,” and this error may have resulted in errant responses. Third, the data collected were descriptive in nature. Thus, the findings are limited by summations and cannot be generalized to the entire population. Finally, in the current study the definitions of the terms “diversity,” “different groups,” and “range of backgrounds” did not include sexual orientation or preference. Research done by Ragins and colleagues (2012) indicate that sexuality is also an important contributor to the diversity climate.

Implications

The current research has many implications for the Midwestern children’s hospital and the growing body of hospital diversity research. There are many benefits to understanding diversity and implementing strategies to create inclusive environments including diversity awareness, opportunities for staff to reflect on their own cultural assumptions, understanding organizational impacts, impacts of diversity on patients and families, and more positive staff attitudes and perceptions.

The current research indicated specific diversity-related items that are most important and valued by participants. This information can be used to implement new policies, improve education programs, and create overall diversity awareness. It was important to find that staff at the Midwestern hospital were optimistic and generally open to discussing diversity. Staff requests for increased education and training and the need for leadership involvement provide specific opportunities for future improvements. Sharing the data and participant responses will be important for leadership to gain understanding of the need for diversity services and cultural competence in the hospital and community setting. Recommending opportunities for training and diversity education will be the priority. These findings and suggested opportunities for improving cultural awareness will be presented at an in-service for any interested staff in order to promote further awareness and provide follow-up.

Future research might include providing diversity education and then offering the questionnaire in order to compare pre- and post-training data. The questionnaire might also be extended to hospital patients and families to assess whether their attitudes and perceptions of diversity match those of employees. Future studies could also focus on assessing policy and organizational change, such as the effect of employing additional interpreters, to examine challenges and changes in the diversity culture.

References


Appendix A

Demographics

<table>
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<tr>
<th>Question</th>
<th>Options</th>
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<tr>
<td>Please indicate the sex for which you identify.</td>
<td>Male, Female, Other</td>
</tr>
<tr>
<td>What is your race/ethnicity?</td>
<td>Fill in the Blank</td>
</tr>
<tr>
<td>What is your age?</td>
<td>Fill in the Blank</td>
</tr>
<tr>
<td>How long have you been employed at this hospital?</td>
<td>Scale starting at &lt; 6 months and ending at &gt;40 years</td>
</tr>
</tbody>
</table>

A Questionnaire for Evaluating Hospital Diversity

This questionnaire provides an overview of issues that are found in the literature on diversity and hospitals. Briefly consider each item according to your experiences within your hospital and department and rate as strongly agree (1), neither agree nor disagree (2), or strongly disagree (3).

Throughout the questionnaire the terms diversity, different groups, and range of backgrounds includes diversity based on ethnicity, language, income, physical ability, mental ability, gender, and religion. The statement “staff and visitors” includes all hospital employees (medical and support), guests, patients, and families.

This questionnaire was adapted from the work of Ginsberg (2004), Weech-Maldonado et al. (2012), Whitman & Valpuesta (2010), and Pearson et al. (2007).

ENVIRONMENT AND MATCHING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patient/family spaces include books, magazines, videos, music, etc. about people from a range of backgrounds.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>2. The artwork around the hospital depicts members of different groups of people.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>3. The hospital accommodates the ethnic/cultural dietary preferences of staff and visitors.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>4. Special events reflect the ethnic and cultural diversity of staff and visitors.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>5. Bulletin boards, social media, and other displays reflect diversity within the hospital.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>6. The hospital creates an environment that supports and welcomes the diversity of all staff, visitors, and the community.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>7. Community representatives routinely involved in the planning and design of the hospital and its services for diverse populations.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>8. The hospital staff matches the diversity of the patients and families served.</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

COMMUNICATION

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. The interpreter services adequately meets the needs of patients and families.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>10. Resources/publications are written from the perspective of diverse groups of people.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>11. Care provided supports values, attitudes, and behaviors of people from diverse backgrounds.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>12. There are a variety of methods used to ensure that all patients/families who speak a language other than English have adequate support for communication.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>13. The hospital tailors patient education materials to different cultural and language groups and all types of learners.</td>
<td>1 2 3</td>
</tr>
<tr>
<td>14. I feel free to discuss diversity issues within my department.</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>
LEADERSHIP AND DIVERSITY EDUCATION

15. The hospital recruits and retains staff members and students from diverse backgrounds. 1 2 3
16. There (or has there been) persons from diverse racial/ethnic backgrounds in leadership positions. 1 2 3
17. In the hospital, support personnel AND medical personnel are trained to identify and care for patients from different cultural backgrounds and who speak different languages. 1 2 3
18. Staff, including leaders, are encouraged to advocate for social justice. 1 2 3
19. I feel the annual employee satisfaction survey measures the diversity climate. 1 2 3
20. Culturally and linguistically diverse services and training should be encouraged by the organization’s leadership. 1 2 3
21. The hospital has formal and ongoing training programs on cultural diversity. 1 2 3

22. Please identify one or two of the previous hospital environment, matching, communication, leadership, or diversity education items that, from your perspective, are most important/critical to diversity within the hospital.

Created and validated by De Meuse and Hostager (2001)

23. Check all the words below that you frequently associate with your current workplace diversity.

<table>
<thead>
<tr>
<th>Compassionate</th>
<th>Ethical</th>
<th>Anger</th>
<th>Unfair</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resentment</td>
<td>Wisdom</td>
<td>Insecurity</td>
<td>Progress</td>
</tr>
<tr>
<td>Unity</td>
<td>Bureaucratic</td>
<td>Proud</td>
<td>Justified</td>
</tr>
<tr>
<td>Stress</td>
<td>Fight</td>
<td>Cooperate</td>
<td>Happy</td>
</tr>
<tr>
<td>Support</td>
<td>Listen</td>
<td>Blame</td>
<td>Rivalry</td>
</tr>
<tr>
<td>Bad</td>
<td>Fear</td>
<td>Lashes</td>
<td>Confused</td>
</tr>
<tr>
<td>Discovery</td>
<td>Sensible</td>
<td>Frustration</td>
<td>Turnover</td>
</tr>
<tr>
<td>Stubbornness</td>
<td>Grateful</td>
<td>Unjustified</td>
<td>Harmony</td>
</tr>
<tr>
<td>Liability</td>
<td>Team-building</td>
<td>Participate</td>
<td>Asset</td>
</tr>
<tr>
<td>Innovation</td>
<td>Expensive</td>
<td>Hopeful</td>
<td>Understand</td>
</tr>
<tr>
<td>Useless</td>
<td>Rewarding</td>
<td>Sacrifice</td>
<td>Worthless</td>
</tr>
<tr>
<td>Unprofitable</td>
<td>Good</td>
<td>Withdrawal</td>
<td>Patronize</td>
</tr>
<tr>
<td>Fair</td>
<td>Pressure</td>
<td>Merit</td>
<td>Enthusiastic</td>
</tr>
<tr>
<td>Excited</td>
<td>Collaborate</td>
<td>Unfriendly</td>
<td>Profitable</td>
</tr>
<tr>
<td>Disorder</td>
<td>Immoral</td>
<td>Regulations</td>
<td>Useful</td>
</tr>
<tr>
<td>Resist</td>
<td>Unnatural</td>
<td>Proper</td>
<td>Disagree</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>Advancement</td>
<td>Enrichment</td>
<td>Apprehensive</td>
</tr>
<tr>
<td></td>
<td>Opportunity</td>
<td>Friendly</td>
<td></td>
</tr>
</tbody>
</table>
Disrupting the Status Quo: 
A New Theoretical Vision for the Child Life Profession

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RYERSON UNIVERSITY

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ABSTRACT

Pediatric patient populations are changing and health care environments are becoming increasingly more complex. Child life professionals must adapt to the realities of today’s health care spaces if they hope to make a difference in the lives of hospitalized children and their families. This paper explores some of the challenges associated with the current ways of thinking and theoretical orientations, which can impede professional growth and psychosocial care as a whole. For example, practice and scholarship continue to be guided by developmental theories, with little regard for how race and other social determinants may affect child health outcomes. As a way forward, child life professionals must consider engaging in a paradigmatic shift whereby new theories and approaches can address the realities of racial disparities and reject the antiquated views of childhood embedded within established developmental theories.

Developmental Theories: Concerns and Limitations

To date, the child life profession has been predominantly guided by developmental stage theories, such as those set forth by Piaget (1959) and Erikson (1963). These theories have shaped our views on how children evolve and adapt to health challenges, and importantly, how we view childhood as a concept or life phase. As a result, child life interventions tend to be informed by developmental assessments that are intended to gauge the level of psychosocial risk associated with childhood illness. The guiding theories are often reinforced in child life educational programs in which students are expected to master and apply the developmental stages to the children they encounter. However, this overreliance on developmental paradigms cannot adequately address the complexity within today’s pediatric settings, and it also limits the ability to explore new avenues of clinical practice and promote professional growth.

Developmental psychology promotes the notion of
a “normal childhood,” but this is based on Western, neoliberal ideologies (Callaghan et al., 2015; Miller & Scholnick, 2015). These ideologies emphasize notions of responsibility, self-regulation, control, and the importance of creating good citizens (Burman, 2017). Theories espousing developmental stages reinforce these ideologies by framing childhood as a universal period of rapid growth whereby young people obtain skills, knowledge, and experience. Children are perceived as progressing through rigid and standardized stages of maturation. As a result, these theories do not adequately represent children who deviate from standardized norms; specifically, certain identities are privileged while others are disparaged (Burman, 2017).

In particular, “sick” children do not fit neatly into a stage theory. They can be viewed as disrupting the dominant ideology. For example, they may be perceived as “abnormal” and less valued than other children and as limited in their ability to meet developmental expectations and contribute to society over time (Black, 2013). Moreover, the conceptualization of childhood as represented in developmental theories does not consider the historical and cultural influences that marginalize children who do not fit the standard. Some scholars, including Miller and Scholnick (2015), have argued that the assumptions on which developmental theories are built cannot be generalized to the wider population.

**Racial Inequity and Child Development Theories**

Traditionally, the interaction of social class, culture, and race has not been central to mainstream theoretical formulations in the field of child development (Garcia-Coll et al., 1996). Stage-based views of development are particularly egregious in their ethnocentric stance. For example, the theories by Piaget and Erikson, arguably the two preeminent theorists of child life pedagogy, have influenced broader social values and failed to acknowledge the compounding impact of structural inequity. The view of child development they uphold is limited in a variety of critical ways, especially when considered within the socio-political, geographical, and historical context of the modern child.

Like the work of Freud (1910), Werner (1948), and other early counterparts, the work of Piaget (1959) and Erikson (1963) promoted a historical parochialism based on the assumption that the patterns and sequences of development prevalent among White middle-class children in contemporary Western societies are the norm of human development (Skolnick, 1975). Several of their most influential concepts—assimilation, accommodation, stages, and causation—are based on the idea that the surrounding environment is static, serving as a mere backdrop, instead of being a complex and formidable force (Skolnick, 1975). The prevalence of laboratory studies in which a child performs an unfamiliar task in a strange situation with a strange adult is both a defining feature of early American developmental psychology and another example of the propensity to minimize or obviate environment. Piaget, for example, determined that observing White boys playing marbles was the most effective way to explore children's ideas about morality and social conventions (Lancy, 2015). Early empirical studies of children in their “ordinary” environments, unless these children reflect Western culture, simply do not exist (Skolnick, 1975).

Socio-cultural context influences all aspects of a child's personhood (Hill & Tisdall, 2014), and yet, the application of mainstream developmental theories in relation to our understanding of how children of color grow and develop has not been embraced at the macro level (Garcia-Coll et al., 1996; Swanson et al., 2009). Therapeutic or developmental interventions influenced by Western developmental theories may not be effective with diverse populations; they may lead child life professionals to mistakenly perceive children's functioning and family or caregiver practices as inadequate or pathological (Miller et al., 2019). It is important to clarify the normal developmental processes of children of color within their unique ecological context, and how these processes are related to the persons who are central to them emotionally.

Bronfenbrenner (1979) developed the Ecological Systems Theory, which emphasizes the influence of environment and the intersectionality of its systems on a child's development, but even it does not make explicit the effects of social mechanisms such as racism, discrimination, and prejudice. This omission has the effect of validating explanations of developmental deviations in comparison to White, middle-class populations. It also threatens the credibility of professionals who adhere to this kind of worldview without questioning the normative developmental processes and outcomes (Garcia-Coll et al., 1996).
Navigating a Racist System

Estimates suggest that by 2050, the majority of the pediatric population in the United States will be children and adolescents from culturally and racially marginalized backgrounds (United States Census Bureau, 2019). However, the nation’s child life workforce continues to be monopolized by White females (Wheelwright, 2018). This problem reflects broader trends within the United States: many of the groups poised to undergo the largest growth are the same groups experiencing lower-quality health care and the blunt force of White supremacy (Smedley et al., 2004). In order for child life professionals to be effective today, they need to engage in a collective conscious-raising about the historical and current contexts in which their patients and families live.

The American Academy of Pediatrics (AAP; Trent et al., 2019) noted the effects of racism on child and adolescent health, stating that the field of pediatrics has not yet systematically addressed the influence of racism on child health outcomes. Clinicians, therefore, are not prepared to identify, manage, mitigate, or prevent risks and harms. Because racism creates significant adverse effects for a variety of individuals, substantial investments in dismantling structural racism are required to facilitate the societal shifts necessary for the optimal development of children (Trent et al., 2019). Research has demonstrated that adverse effects from segregation and discrimination disproportionately expose Black children to poverty and more stressful environments, which in turn, affects their health (Umberson et al., 2014).

Racism proliferates in various forms in nearly all countries and cannot be examined in isolation; it is often linked to forms of oppression based on sexism, religious persecution, political conflict, economic exploitation, or international conflict (Castles, 1993). The work of the dismantling of oppressive systems thereby begins with the acknowledgement that oppression is embedded in society and is followed by a commitment to understanding how the massive historical trauma associated with it continues to shape the lives of individual children, families, communities, and the systems with which they interact (National Child Traumatic Stress Network, 2019). Self-interrogation, self-awareness about one’s social location and its influence on the work, and a willingness to overcome the disequilibrium that can accompany direct communication about these issues are fundamental components to the path forward (National Child Traumatic Stress Network, 2019). Conceptual frameworks that fail to address the effects of racism, discrimination, and oppression on the development of children in families of color not only hamper the ability of a child life specialist to intervene effectively, they also promote a narrow and reductive worldview.

Increasing Numbers of Children in Complex Care

The future of pediatric health care is not only being shaped by increasing diversity and racial disparity; clinical and technological advancements in medicine have prolonged the life expectancy of many children with chronic conditions. As a result, more children require multidisciplinary care and coordination of services. For this reason, terminology regarding pediatric populations is changing, and some children with special health care needs are now referred to as children with medical complexity (Cohen et al., 2018).

Children with medical complexity have been the subject of considerable attention in recent years. Many have serious chronic conditions, substantial functional limitations, and extensive health and other service needs, which amount to high health care costs and resource consumption (Berry et al., 2015; Cohen et al., 2018). Because children requiring complex care are hospitalized frequently and for long periods of time, they consume most of the available pediatric health care resources (Cohen & Patel, 2014; Davies, 2010; Hessels et al., 2017; James & Curtis, 2012). A key component of effective long-term care is coordination of care (Matlow et al., 2006), and these children require policy and programmatic interventions that differ in many ways from broader populations of children with special health care needs (Cohen et al., 2018).

As the number of these children increases, it is becoming more important for child life professionals to reflect on the implications of long-term pediatric complex care. For example, how is the child life profession currently addressing the emergence of pediatric complex care within marginalized populations? Are practitioners and researchers considering best practices that support the inclusion of child life care in the coordination of care? How will complex pediatric care shape and affect the quality of relationships with children and families over time?
Considering Alternate Theories: A New Theoretical Vision for the Child Life Profession

In the 1990s, an alternative framework emerged in reaction to the pitfalls of developmental theories: the sociology of childhood (James & Prout, 1997). The broader discipline of sociology focuses on explaining the social world (Ingleby, 2012), specifically social processes and social structures (Thomas, 2014). The sociology of childhood is based on the premise that the concept of childhood is a social construction: it is dependent upon historical, political, and social contexts (Black, 2013; James & Curtis, 2012). From this perspective, young people are constantly constrained by societal, political, and economic conditions, but given the opportunity, they can become social agents of change in their own lives. This is in direct contrast with developmental theories framing childhood as a period of dependence and vulnerability and involving a stage-like progression to adulthood; this kind of traditional framework was cultivated solely by adults and devalues the inherent meaning of childhood.

From Seeking Legitimacy to Creating a Paradigmatic Shift

The child life profession arose in response to historically difficult health care environments that did not always welcome the provision of psychosocial care (Davies, 2010). In its early stages, it was particularly strategic for child life professionals to align themselves with those in powerful positions within pediatrics. At the time, popular theories were based on developmental psychology, which drew from research involving predominantly White, North American populations (Nielsen et al., 2017). Child life professionals embraced developmental theories as a way to seek legitimacy and validation in the health care environment, which led to various child life practices including developmental screening, therapeutic play, and a philosophy based on family-centered care (Koller, 2017, 2018; Koller & Goldman, 2012). The main goal was to optimize normal development for sick children, and developmental paradigms have continued to dominate child life scholarship, discourse, and practice.

Paradigms are defined as systems of thought with sets of assumptions that determine how people perceive the world (Amatucci et al., 2013). Tensions can arise when experiences and information do not match an existing paradigm: People tend to personalize and invest in a prevailing paradigm and feel threatened by anything or anyone that tries to change or dislodge it (Barker, 1993; Kuhn, 1970). They assume that because the paradigm has been successful in the past, it will continue to be so, given more time or resources (Barker, 1993). This kind of inability or refusal to see beyond current modes of thinking may be the greatest barrier to paradigm shifts (Harrison et al., 2017; Kuhn, 1962, 1970, 1996; Smith, 2006). Paradigms must deliver solutions to problems and changes faced in the workplace: If new challenges arise and the current paradigm is unable to resolve them, professionals must consider innovative approaches that can eventually lead to a new paradigm (Kuhn, 1962, 1970, 1996). This process requires a collective will to expose, explore, and reconsider the root structures of the old paradigm.

Child life practices are a vital component of progressive psychosocial care for children. To date, however, there have been no overt calls for a shift in thinking, or even a critical inquiry of foundational theories. The persistent reliance on developmental theories as foundational to child life practice represents a serious threat to the child life reputation as pediatric professionals who operate on the premise of best practices and evolving evidence. As a consequence, growth in the profession is constrained, while children’s agency and participation in health care settings are undermined.

Professionals engaged in child life research, practice, and teaching must submit to a critical and reflective evaluation of foundational theories, while being open to new paradigms that are grounded in current, empirical and practice-based evidence. In particular, child life theories and perspectives must account for evolving views of childhood that address issues of race and social contexts. Trends in pediatrics include increasing numbers of children requiring complex care and confirmation that structural oppression shortens lifespans (Duru et al., 2012). If child life specialists believe every child has the right to the best psychosocial care, then child life specialists must openly acknowledge the ever-metastasizing impact of racism on children’s health outcomes.

In conclusion, the only way the child life profession can safeguard ethical care is to engage in a critical and perhaps difficult examination of the entrenched belief systems and theoretical orientations. Otherwise, as
a profession with predominantly White females, the child life profession becomes complicit in ignoring racial disparities when childhood is defined as a distinct stage of development whereby all children are measured against the same standards. The time to begin the necessary work of professional self-examination is long overdue. A collective commitment to do better will not only strengthen the profession, it will enable all children and families to be seen in the full expression of their humanity.

References


United States Census Bureau, (2019). *Table DP05*. https://data.census.gov/


The Transferability of Goal Attainment Scaling (GAS) for Child Life Specialists Working in Pediatric Rehabilitation: A Critical Review of the Literature

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MCMASTER UNIVERSITY

ABSTRACT

There is much variation in the way child life specialists implement and document their interventions and services, especially among practice arenas. This variation includes the methods child life specialists use to set individual goals with pediatric clients and families, as well as to evaluate the effectiveness of their interventions and services. The purpose of this paper is to highlight how goal attainment scaling (GAS) could and should be integrated into the daily practices of child life specialists working in a pediatric rehabilitation setting. GAS is a widely used individualized outcome measure, designed to assess whether individuals have achieved the goals of intervention by quantifying their progress (Kiresuk & Sherman, 1968). As there is currently no literature on the integration or utility of GAS as an outcome measure for child life specialists, this paper will critically examine the available peer-reviewed literature to demonstrate how and why GAS is currently being implemented in pediatric rehabilitative settings by other health care practitioners. Recommendations for the transferability of GAS in child life practice will subsequently be discussed to not only address this gap in knowledge, but to further emphasize the benefits of using an individualized outcome measure in clinical practice.

Introduction

In pediatric rehabilitation, goal setting is a core process that is frequently used by a variety of health care practitioners, as it is strengths-based and solutions-focused and promotes patient- and family-centered care (Bovend’Eerdt et al., 2009). Patient- and family-centered care has become a widely accepted form of service delivery and is considered a best practice (Bell et al., 2009; Bexelius et al., 2018; Calder et al., 2018; Øien et al., 2010; Rosenbaum et al., 1998). Goal setting approaches are focused on enhancing the health care experience by cultivating partnerships between clients, families, and practitioners, as each individual can bring a unique perspective (Bell et al., 2009; Calder et al., 2018; Rosenbaum et al., 1998).

Goal setting is essential in pediatric rehabilitation, as it not only identifies what is most important to the client and family, but it also allows members of the care team to be aware of the identified goals, the effective methods being used to help the client attain them, and each team members’ role and relevance in meeting the client’s unique needs (Bexelius et al., 2018; Bovend’Eerdt et al., 2009). However, when goal setting is used in clinical practice, it is often vague, biased, irrelevant, unreliable, time consuming, and done without adhering to a formal framework (Angeli et al., 2019; Bovend’Eerdt et al., 2009; McDougall & King, 2007; McDougall & Wright, 2009). Therefore, when practitioners are setting goals with clients and families, they should be developed, monitored, and evaluated in thoughtful and systematic ways to ensure they are meaningful and relevant and that the aim of the interventions are clear (King, et al., 2000a; Scobbie et al., 2009). As patient- and family-centered care is considered best practice in pediatric rehabilitation, it can be challenging for practitioners to find formal
evaluation tools that can reflect personalized care plans and account for individualized goals (Angeli et al., 2019; Bexelius et al., 2018; Harpster et al., 2018).

Goal attainment scaling (GAS) is an individualized outcome measurement tool that has become increasingly popular in the field of pediatric rehabilitation, as it “facilitates the translation of clients identified needs into distinct, measurable goals set collaboratively by clients and their families and service providers” (McDougall & Wright, 2009, p. 1362). This is significant as goal setting has been shown to help improve clients’ commitment, motivation, and progress towards meeting their rehabilitation goals (Krasny-Pacini et al., 2013). This methodology was originally developed by Kiresuk and Sherman (1968) as a tool to evaluate community mental health services. Their methodology is free to access and can be found in their original article, as well as in many research articles and formal GAS resource guides. Kiresuk and Sherman’s (1968) 5-point rating GAS methodology has since been used to evaluate health services and educational programs, as well as used to measure intervention-induced change in a variety of practice arenas where goal setting can inform treatment planning, including special education, nursing, social work, chronic pain, psychiatry, geriatrics, and pediatric rehabilitation (Harpster et al., 2018; King, et al., 2000a; King, et al., 2000b; Krasny-Pacini et al., 2013; McDougall & Wright, 2009; Turner-Stokes, 2009).

When looking to develop personalized GAS scales for individual clients, first an observable goal needs to be identified and defined, along with the client’s baseline performance level with respect to the chosen goal (Krasny-Pacini et al., 2013). A range of potential goal attainment outcomes will then need to be defined and organized onto a 5-point rating scale, ranging from -2 to +2, where a specific number value is assigned to an outcome following an intervention or service (Harpster et al., 2018; Krasny-Pacini et al., 2013; McDougall & Wright, 2007; McDougall & Wright, 2009; Turner-Stokes, 2009). See Figure 1 for an explanation of the representation of each of the five levels.

When using GAS methodology, there are expected goal setting and goal rating applications. For example, in Figure 2, each 5-point GAS scale should represent one goal and only have one variable of change and should be created with equal intervals between each of the five levels of goal attainment (Harpster et al., 2018; McDougall & King, 2007; McDougall & Wright, 2009; Turner-Stokes, 2009). This is important, as goal attainment from level +1 to +2 should not be any more challenging or require a larger change in performance than progress from level -2 to -1 (McDougall & King, 2007). In addition, it is typical for three GAS goals (each represented by their own individual 5-point rating scale) to be developed for each client (Turner-Stokes, 2009).

<table>
<thead>
<tr>
<th>Attainment Level</th>
<th>Score</th>
<th>Physiotherapy Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>-2</td>
<td>Is able to walk to the gym from classroom and back with no aids in 15 minutes falling 8 times</td>
</tr>
<tr>
<td>Less than Expected Outcome</td>
<td>-1</td>
<td>Is able to walk to the gym from classroom and back with no aids in 15 minutes falling 6 times</td>
</tr>
<tr>
<td>Expected Outcome</td>
<td>0</td>
<td>Is able to walk to the gym from classroom and back with no aids in 15 minutes falling 4 times</td>
</tr>
<tr>
<td>Greater than Expected Outcome</td>
<td>+1</td>
<td>Is able to walk to the gym from classroom and back with no aids in 15 minutes falling 2 times</td>
</tr>
<tr>
<td>Most Favorable Outcome Likely</td>
<td>+2</td>
<td>Is able to walk to the gym from classroom and back with no aids in 15 minutes falling 1 time</td>
</tr>
</tbody>
</table>

According to Mertens and Wilson (2012), a GAS scale can be used for three purposes: (1) to evaluate and/or monitor a client’s progress towards goal attainment; (2) to assess the effectiveness of an intervention being implemented; or (3) to evaluate the program.
that is providing an intervention. In clinical practice, a client’s performance is typically observed and then rated by a practitioner or multidisciplinary health care team member, which can include the client and the family (McDougall & King, 2007). For evaluation purposes, the goals can be weighed and scored according to importance (as determined by the client and/or family) and difficulty (as rated by the practitioner) by using a formula developed by Kiresuk and Sherman (1968; Bovend’Eerdt et al., 2009; Harpster et al., 2018). The importance and difficulty scores are then used to calculate a mean aggregate T score, where a score of 50 or above typically indicates a clinically significant improvement in goal performance (Harpster et al., 2018; King, et al., 2000a; Steenbeek, et al., 2007; Turner-Stokes, 2009).

Goal setting and scale construction are frequently noted to be challenging, as scales can be very time-consuming to create and a client’s performance can be difficult to predict (Bexelius et al., 2018; McDougall & Wright, 2009; Steenbeek et al., 2011). While the literature consistently mentions the importance of applying the methodology effectively to minimize bias in both scale construction (e.g., creating scales that are too easy or too challenging) and in rating the client’s performance (e.g., showing inaccurate or false goal attainment), apart from formal user guides, very few articles have actually described their training or GAS orientation process (Harpster et al., 2018; McDougall & King, 2007; McDougall & Wright, 2009; Steenbeek et al., 2007). McDougall and King’s (2007) resource guide suggests that practitioners wishing to use GAS methodology should engage in two hours of training procedures, followed by 10 additional hours of skill building to gain more proficiency in both goal setting and goal rating.

In the existing literature, many members of the multidisciplinary health care team working in pediatric rehabilitation are already familiar with GAS methodology in setting meaningful goals with clients and families. However, child life specialists, who are also valued members of the health care team, have not been shown to utilize such methods in their daily practice. Their focus in many practice arenas, including pediatric rehabilitation settings, is to “help infants, children, youth and families cope with the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss and bereavement” (Association of Child Life Professionals, 2019). Some common therapeutic interventions that are offered and facilitated by child life specialists to help promote coping include delivering developmentally appropriate psychological preparations for procedures and transitions; providing medical, therapeutic, and normative play opportunities; encouraging healthy expression of feelings; and exploring existing and developing new effective coping strategies (Association of Child Life Professionals, 2019). As child life specialists operate within the context of patient- and family-centered care and aim to improve their clients’ coping and functional outcomes by helping them identify and make progress towards their goals, it is surprising there is no literature on the utility or application of GAS in child life clinical practice. Therefore, it is essential to examine the available peer-reviewed literature to identify the recent applications of GAS in pediatric rehabilitation, as it is hypothesized that GAS would be an effective outcome measure for child life specialists working in this setting.

Theories and Frameworks

Social Cognitive Theory and Goal-Setting Theory

Bandura’s Social Cognitive Theory (1997), specifically the self-efficacy component, as well as Locke and Latham’s Goal-Setting Theory (2002), are two specific frameworks that underpin the development and evaluation of individually tailored interventions (Scobbie et al., 2009). Self-efficacy refers to how confident an individual is in their ability to achieve their goals, and Goal-Setting Theory speaks to how goal specificity, level of difficulty, and performance feedback can directly influence goal-related behavior (Scobbie et al., 2009). According to Locke and Latham (2002), their theory is consistent with Bandura’s Social Cognitive Theory (1997), as both acknowledge the importance of self-efficacy in goal setting. As these two theories can be used to help understand, predict, and inform the practice of setting goals, they could also be used to inform the transferability and utility of GAS, as it is known that goals are more likely to be attained if clients and families are actively involved in the goal-setting process (Scobbie et al., 2009; Krasny-Pacini et al., 2013; Turner-Stokes, 2009).

The International Classification of Functioning, Disability, and Health

The International Classification of Functioning, Disability, and Health: Child and Youth Version (ICF-CY; World Health Organization, 2007) is a universal
classification system that considers the intersectionality and bidirectional relationship between an individual’s contextual factors and their health condition (Rosenbaum & Stewart, 2004). Rather than solely focusing on an individual’s biomedical impairments or functional limitations, the ICF-CY places great emphasis on one’s assets and capabilities. In addition to the two previously mentioned theories, the ICF-CY can also be used to inform the use of GAS, as well as to influence collaborative goal setting in child life practice. The ICF-CY can provide a positive patient-and family-centered conceptual framework through which clients, families, and practitioners can together identify goals and functional outcomes (McDougall & Wright, 2009). The ICF-CY relies on a biopsychosocial and holistic perspective of health, functioning, and disability and is already a frequently used teaching tool and framework in both clinical and research-based settings (McDougall & Wright, 2009; Rosenbaum and Stewart, 2004). The domains within this classification system can be used to inform both goal setting and goal rating, as practitioners should be implementing interventions that consider each client’s strengths, health condition, participation, functional ability, desired functional outcomes, and contextual factors (both environmental and personal; Rosenbaum & Stewart, 2004). Instead of setting vague goals that may not relate to the context of a client’s life and development, the ICF-CY can encourage targeted goal-setting in relation to each client’s level of functioning, activity limitations, participation restrictions, environmental factors, and personal factors (McDougall & Wright, 2009; World Health Organization, 2007).

**Methods**

Targeted searches were conducted on Google Scholar, CINAHL, PubMed, Ovid, and Web of Science using different combinations of search terms such as “outcome measures,” “goal setting,” “goal attainment scaling,” “program evaluation,” and “pediatric rehabilitation.” The reference pages of retrieved studies were also examined to identify relevant articles. Publication types, dates, and peer-reviewed articles in English were also filtered to identify the most rigorous and evidence-based resources available. The review included all disciplines in the field of pediatric rehabilitation, including physical, occupational, and speech-language therapy, as well as the application of GAS in community-based school and therapy settings. The decision to include these settings assumed that GAS has broad applications and such evidence could further emphasize the flexible nature of the tool.

The search process initially resulted in 29 articles; however, 10 were more than 20 years old and were not specific to pediatric rehabilitation. A second search was conducted to retrieve more systematic reviews, meta-analyses, or randomized control trials. As a result, additional randomized control trials with high methodological quality were found. The Critical Appraisal Skills Programme (2018) checklists were subsequently used to critically appraise the retrieved systematic reviews and randomized control trials, as well as the cohort and case control studies, to further assess the rigor and validity of each article. The articles were then assigned a level corresponding to Melnyk and Fineout-Overholt’s (2015) levels of evidence hierarchy. Twelve relevant articles remained that relate to the research topic and inclusion criteria specific to this literature review. However, this number is not exhaustive, as additional peer-reviewed literature reviews, resource guides, and textbooks were also examined and included in this review.

**Results**

**Recent Uses of Goal Attainment Scaling in Pediatric Rehabilitation**

In a systematic review by Harpster et al. (2018), the authors included 52 studies that used GAS as a tool to measure and evaluate the effectiveness of physical and occupational therapy interventions within a pediatric rehabilitation setting. The results from the review indicated that while 17 randomized control trials were included, 33 of the 52 studies were classified as low-level (IV or V) according to Sackett’s hierarchy of evidence (1986; Harpster et al., 2018). Five-point GAS scales were used to assess a variety of therapy services for pediatric clients ranging from four months to 19 years of age, with diagnoses including cerebral palsy, traumatic brain injury, ADHD, and other developmental diagnoses (Harpster et al., 2018). Out of all diagnoses, the most common was cerebral palsy, representing 34 of the 52 studies, with the most reported intervention being goal-directed therapy (Harpster et al., 2018). The results from the review highlighted that while GAS appeared to detect small and meaningful change following an intervention and is consistently used to document progress toward the attainment of specific and relevant client-identified goals in a variety of interventions and diagnoses, the
majority of studies used low to moderate methodological rigor in their designs (Harpster et al., 2018).

The findings from the systematic review were consistent with many critical literature reviews (King et al., 2000a; Mailloux et al., 2007; Steenbeek et al., 2007; Tennant, 2007). Please refer to Table 1. Such reviews demonstrated that while GAS is a useful tool for measuring therapeutic change and can be used for a variety of interventions, diagnoses, and disciplines, psychometric concerns regarding the tool’s reliability (content and interrater) and validity (construct, content, convergent, and concurrent) are raised when the tool is not applied with enough precision or adequate training (King et al., 2000a; Mailloux et al., 2007; Steenbeek et al., 2007; Tennant, 2007). Mailloux et al. (2007) and Steenbeek et al. (2007) purported that these findings are not surprising, as GAS is a highly individualized measure; however, they also stated that formal resource guides such as McDougall and King’s (2007) and Turner-Stokes’ (2009) should be consulted, as they can provide specific recommendations to help practitioners apply GAS methodology appropriately and effectively.

In Angeli and colleagues’ (2019) retrospective chart review of GAS goals, the authors looked at the goal-setting process of 124 clients, aged two to 32 years who participated in episodic care programs. Clients received multidisciplinary therapy for approximately three months over an average of 11 visits. Clients presented with a range of disabilities including cerebral palsy, muscle weakness, developmental coordination disorder, hemiparesis, and language disorder (Angeli et al., 2019). The study analyzed 656 developmental therapy goals (averaging four goals per client) using 5-point rating GAS scales and found that half of the goals were solely established by the caregiver, 10% by the client, and the rest were established by unknown goal setter(s), possibly a combination of the caregiver, the client, and/or the practitioner(s) (Angeli et al., 2019). With respect to GAS, the results indicated that the goals established solely by the caregiver focused more on future-oriented problems, whereas the clients typically focused on more immediate problems (Angeli et al., 2019). This study is consistent with another relevant study by Vroland-Nordstrand et al. (2015), as it relates to collaborative goal setting and emphasizes the importance of including both the client’s and the family’s preferences when establishing goals. In this study, Vroland-Nordstrand and colleagues (2015) used an assessor-blinded, parallel, randomized design to evaluate the efficacy of client-identified goals and parent-identified goals on a goal-directed occupational therapy intervention. Thirty-four children with disabilities such as movement disorder, learning disability, and autism were included in the two, eight-week intervention groups, where one group used client-identified goals and the other used parent-identified goals (Vroland-Nordstrand et al., 2015). GAS was used in combination with the Canadian Occupational Performance Measure (COPM), which is a standardized outcome measure that is commonly used by occupational therapists to collect information about a client’s goal progress in areas relating to their activities of daily living (McDougall & Wright, 2009; Vroland-Nordstrand et al., 2015). The study found that 79% of the client-identified group goals were reached at the expected level or higher, whereas 61% were achieved in the parent-identified group (Vroland-Nordstrand et al., 2015). This demonstrates the value and benefit of including pediatric clients and their preferences when setting high-quality goals with practitioners (Vroland-Nordstrand et al., 2015).

Several researchers (Bexelius et al., 2018; Bovend’Eerdt et al., 2009; Steenbeek et al., 2007, 2011; Krasny-Pacini et al., 2013; Turner-Stokes, 2009) recommend the use of SMART goals (smart, measurable, achievable, relevant, and timed) to help practitioners construct high-quality goals. In a retrospective multi-case study written by Bexelius et al. (2018), which included 42 children with a range of disabilities including cerebral palsy, Down syndrome, and other developmental disabilities, the participants received eight to 12 weeks of goal-directed multidisciplinary therapy (physiotherapy, occupational, speech-language therapy, and special education). The results showed that when SMART GAS goals were collaboratively set with the family, they were considered relevant by both the family and the practitioner. While formulating SMART goals can be challenging and time-consuming, the process can provide a clear and standardized approach to help ensure that the goals are not only meaningful to clients, families, and practitioners, but can also be used to try to minimize bias when constructing scales (Bexelius et al., 2018). However, the majority of the articles mentioned the need for formal training and practice in the use of GAS methodology in order to ensure good reliability and validity (Harpster et al., 2018; McDougall & Wright, 2009; Steenbeek et al., 2007).
In a study by Law et al. (2004), the responsiveness, reliability, and content validity of GAS was studied. Three individualized functional goals were created for 25 children ages one to six years with cerebral palsy, where each received a four-month intervention based on conductive education. The goals were written as behavioural objectives, as well as in a 5-point GAS scale format. The authors found GAS had good content validity, reliability, and was more responsive to change than the corresponding behavioural objectives (Law et al., 2004). Each child had pre- and post-test assessments for their gross motor functional performance, neuromuscular condition, and cognitive level using the Gross Motor Function Measure (GMFM; Law et al., 2004), a commonly used standardized outcome instrument designed to evaluate changes in the gross motor functioning of children living with cerebral palsy. In the study, the goals were collaboratively set with the child, the child’s family, and the multidisciplinary care team. The overall results of the study supported the use of GAS in monitoring and evaluating motor changes of children with cerebral palsy (Law et al., 2004). The results also affirmed that GAS can provide precise information to practitioners wishing to evaluate the effectiveness of an intervention or monitor the progress of a client, as it encourages realistic goal setting (Law et al., 2004). Law et al. (2004) stated that “unlike standardized norm-referenced evaluative tools, GAS is a flexible set of procedures for evaluating change in individual performance” (Law et al., 2004, p. 27). Based on their findings, it was suggested that GAS might be used to complement other standardized outcome measures, such as the GMFM, or they could be used independently to replace behavioural objectives (Law et al., 2004).

### Comparison of GAS and other Outcome Measures

As the combined use of GAS with other outcome measures such as the GMFM has been previously mentioned, literature reviews such as McDougall and Wright (2009) have also proposed the combined use of GAS and the ICF-CY. Such combined approaches may be beneficial as they can help standardize, as well as individualize the assessment and outcome evaluation practices (McDougall & Wright, 2009).

While there is evidence to support the benefits associated with the combined use of GAS with other standardized outcomes or frameworks, the literature also

Table 1. Recent Uses of Goal Attainment Scaling (GAS) in Pediatric Rehabilitation

<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention</th>
<th>Population</th>
<th>Design</th>
<th>Results</th>
<th>Conclusion of Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angeli et al., 2019</td>
<td>Task-oriented PT/OT interventions</td>
<td>124 children with DD</td>
<td>Retrospective</td>
<td>Decreased level of assistance was a robust dimension of change</td>
<td>Evidence supports use of collaborative goal-setting and client/family preferences in goal-setting</td>
</tr>
<tr>
<td>Bexelius et al., 2018</td>
<td>Goal-directed multidisciplinary therapy</td>
<td>42 children with CP, down syndrome, DD</td>
<td>Retrospective multicase study</td>
<td>All goals reliably linked to ICF</td>
<td>Goals set with SMART criteria showed high quality</td>
</tr>
<tr>
<td>Harpster et al., 2018</td>
<td>Studies targeting effectiveness of PT/OT interventions</td>
<td>52 studies were reviewed</td>
<td>Systematic review</td>
<td>GAS was clinically useful but not a lot of methodological rigor in research</td>
<td>GAS can be used for a variety of diagnoses and interventions</td>
</tr>
<tr>
<td>Law et al., 2004</td>
<td>Conductive education</td>
<td>25 children with CP</td>
<td>Longitudinal pre/post design</td>
<td>GAS was more useful than BO in monitoring client progress and intervention effectiveness</td>
<td>GAS was applicable to children with CP given its reliability, responsiveness, and validity</td>
</tr>
<tr>
<td>Vroland-Nordstrand et al., 2016</td>
<td>Goal-directed OT interventions</td>
<td>34 children with LD, MD, ASD</td>
<td>Randomized control trial</td>
<td>16/17 children reached expected goal or higher on GAS in child-goal group</td>
<td>Higher goal achievement in child-identified goal group compared to parent-identified goal group, which supports the inclusion of children in the goal-setting process</td>
</tr>
</tbody>
</table>

Abbreviations: GAS, Goal Attainment Scaling; CP, Cerebral Palsy; DD, Developmental Disabilities; PT, Physical Therapy; OT, Occupational Therapy; ICF, International Classification of Functioning, Disability and Health; BO, Behavioural Objectives; LD, Learning Disability; MD, Movement Disorder; ASD, Autism Spectrum Disorder
suggests that the use of GAS as an individualized measure is more sensitive and responsive to small changes in performance compared to the use of standardized measures alone (Harpster et al., 2018; McDougall & Wright, 2009; Miller et al., 2007; Steenbeek et al., 2011). Please refer to Table 2. Standardized measures are often used to assess and monitor a client pre- and post-intervention to measure changes following an intervention or service; however, these measures usually focus on one aspect of a client’s health and may not take an individual client’s or family’s needs, goals, and preferences into account (McDougall & Wright, 2009). Apart from the differences in sensitivity and responsiveness, standardized outcome measures also tend to have floor and ceiling effects (Turner-Stokes, 2009). Due to these effects, according to McDougall and Wright (2009), standardized measures are often modified or tailored to better suit a client’s needs and/or situation; however, individualizing standardized measures may impact its psychometric properties. This could be an indication as to why so many practitioners are incorporating individualized outcome measures into their daily practice or are using them in combination with standardized outcome measures.

In a randomized control trial by Cusick et al. (2006), GAS was compared to the COPM, using an adapted version of the original GAS methodology that employed a 7-point rating scale to further increase the sensitivity of the scale. A two-group pre- and post-design was used to evaluate the impact of a three-month occupational program involving 41 children with cerebral palsy. The results from the study demonstrated that both instruments are robust and sensitive to within-group change, and both detected significant between-group change (Cusick et al., 2006). However, GAS was shown to be more flexible and therefore preferable if a study required unique or family-generated goals, while the COPM was shown to be more time-efficient when it came to training practitioners on its use and developing scales (Cusick et al., 2006). These findings were consistent with an observational pre- and post-test study conducted by Steenbeek et al. (2011), where they assessed the responsiveness of a 6-point GAS scale compared with the GMFM and the Pediatric Evaluation of Disability Inventory (PEDI). The PEDI is another standardized performance measurement tool; however, it is used to evaluate both the capability and performance of functional activities relating to self-care, mobility, and social functioning (Steenbeek et al., 2011). In this study, the 5-point GAS scale was modified into a 6-point rating scale to account for the potential deterioration of a client’s baseline performance, which was represented by “-3.” Twenty-three children with cerebral palsy, aged two to 13 years, participated in six months of physical, occupational, and speech-language therapy, and the three measures were used pre- and post-treatment. The results showed that 20% of GAS items were not covered by items of the PEDI or the GMFM, indicating that relying solely on standardized measures could have excluded relevant or meaningful rehabilitation goals (Steenbeek et al., 2011).

In a randomized control trial, Miller et al. (2007) evaluated the effectiveness of three occupational therapy treatment groups (occupational therapy, alternate treatment, and no treatment) using a sensory integration approach on 24 children with sensory modulation disorder. Five standardized outcome measures were administered pre- and post-treatment to assess behavior, sensory and adaptive functioning, and

Table 2. Comparison of GAS and other Outcome Measures

<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention</th>
<th>Population</th>
<th>Design</th>
<th>Results</th>
<th>Conclusion of Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cusick et al., 2006</td>
<td>Use of Botox and OT</td>
<td>41 children with spastic CP</td>
<td>Randomized control trial</td>
<td>GAS detected significant changes between groups</td>
<td>Both GAS and COPM were sensitive to change after intervention</td>
</tr>
<tr>
<td>Steenbeek et al., 2011</td>
<td>Multidisciplinary therapy</td>
<td>23 children with CP</td>
<td>Longitudinal pre/post design</td>
<td>GAS scales scored complete goal attainment</td>
<td>GAS, PEDI, and GMFM were complementary as evaluative outcome tools</td>
</tr>
<tr>
<td>Miller et al., 2007</td>
<td>OT</td>
<td>24 children with sensory modulation disorder</td>
<td>Randomized control trial</td>
<td>OT-SI approach may be effective in ameliorating difficulties of children with SMD</td>
<td>GAS was most meaningful and sensitive outcome measure in study</td>
</tr>
</tbody>
</table>

Abbreviations: GAS, Goal Attainment Scaling; CP, Cerebral Palsy; PEDI, Pediatric Evaluation of Disability Inventory; GMFM, Gross Motor Function Measure; SMD, Sensory Modulation Disorder; OT-SI, occupational therapy sensory integration; OT, occupational therapy
sympathetic nervous system activity (Miller et al., 2007). GAS was used as an individualized outcome measure by subjects’ parents, with assistance from the study’s primary interviewer to determine and rank-order five goals that identified changes deemed achievable over 20 sessions (Miller et al., 2007). A trained practitioner wrote the GAS items and defined the five levels of possible goal attainment for each participant. Not only did the results indicate that an occupational therapy sensory integration approach may be effective for children living with sensory modulation disorders, but the study also demonstrated that out of all the outcome measures used, GAS was the most meaningful and sensitive (Miller et al., 2007).

Recent Uses of GAS in Alternative Settings
A longitudinal descriptive study by Chiarello et al. (2016) included 109 physical therapists and 296 students, aged five to seven years, with disabilities, including cerebral palsy, Down syndrome, and global developmental delay. The purpose of the study was to describe the individualized outcomes for each student receiving school-based physical therapy services (Chiarello et al., 2016). Using GAS as the outcome measurement tool, and each student having one to four goals, the findings showed that some students made progress, achieved, and even surpassed their expected functional, adaptive, and academic-related goals (Chiarello et al., 2016). These results demonstrated that meaningful and individualized goal setting can help support student outcomes (Chiarello et al., 2016). In King and colleagues’ (2000b) feasibility study, the effects of multidisciplinary therapy services provided in a school-based setting were evaluated. The study involved collaborative and meaningful goal setting between the parents, practitioners, and teachers of 16 students with physical or communication needs, for 13 therapy sessions over a four to five-month period (King et al., 2000b). The study found that the 5-point rating GAS methodology was a suitable outcome measurement tool and that the majority of children showed expected or greater than expected improvement on their GAS goals (King et al., 2000b). The authors highlighted that “therapy services targeting functional goals can have important effects on children’s goal attainment and level of functioning in the school setting” (King et al., 2000b, p. 20).

Chiarello and colleagues’ (2016) and King and colleagues’ (2000b) findings are also consistent with those found in Keenan and colleagues’ (2014) retrospective study, in that goal-focused and community-based interventions were shown to support functional outcomes and skill development. Keenan et al. (2014) used GAS in combination with the COPM to evaluate the effectiveness of group-based and one-on-one life skills coaching interventions for 50 youths, aged 15 to 21 years, living with a disability such as cerebral palsy, spina bifida, acquired brain injury, or autism. The results indicated that experiential, community-based coaching interventions were effective, and found the combined use of the COPM and GAS provided different but complementary perspectives on the same goal area (Keenan et al., 2014). These findings are consistent with the available research supporting the combined use of GAS and COPM. However, Keenan and colleagues’ (2014) findings that pointed to GAS and COPM having different perspectives on the same goal area are somewhat inconsistent with Cusick and colleagues’ (2004) finding that the two instruments measured different goal areas altogether. This may be due to Keenan et al. (2014) implementing the COPM first and then developing a GAS goal based on the results, whereas Cusick et al. (2004) created the GAS goal first and then implemented the COPM.

Apart from school-based therapy services, GAS has also been frequently used in early childhood intervention services (Calder et al., 2018). Please refer to Table 3. Calder et al. (2018) conducted a systematic review to examine the use of outcome measures in evaluating the effectiveness of multidisciplinary early childhood interventions. From their search, 10 studies were used, and 14 outcome measures were identified. Of those measures, eight, including GAS, were recommended in the early intervention literature and were considered multidimensional and authentic with moderate to strong robustness (Calder et al., 2018). The methodological quality of the studies included were mixed; however, they were consistent with the existing literature. According to the authors, “GAS has been identified as clinically useful in documenting change over time and is more sensitive to change than normative measures” (Calder et al., 2018). The review also notes the same psychometric concerns that are raised in the available research which relate to user/practitioner bias and the need for adequate training to improve the application of GAS methodology (Calder et al., 2018). In addition to formal training and orientation to GAS method-
The aim of this literature review was to examine the current utility and recent applications of GAS in pediatric rehabilitation to support its transferability into child life practice. The retrieved articles for this review were consistent in their descriptions, definitions, and psychometric limitations of GAS, as well as in their use of the original GAS 5-point rating scale (apart from the Steenbeek et al. [2011] study, which employed a 6-point rating scale and the Cusick et al. [2006] study, which used a 7-point GAS scale). However, the purposes, study designs, and methodological rigor when applying GAS were mixed. Sample sizes for the included studies ranged from 16 to 296 participants, with ages ranging from four months to 32 years and diagnoses including cerebral palsy, fine motor difficulty, sensory modulation disorder, acquired brain injury, autism spectrum disorder, developmental delay, developmental coordination disorder, articulation difficulties, learning disability, hemiparesis, and movement disorder. With such a wide range of ages and diagnoses, the results demonstrate that GAS can be used with infants as young as four months of age, as it is an individualized evaluation tool that is capable of detecting small but meaningful changes in performance (King et al., 2000a; McDougall & King, 2007; Miller et al., 2007). The interventions used in the studies included physical, occupational, and speech-language therapy; goal-directed therapy; conductive education; sensory integration activities; school-based therapy; life skills coaching; and early childhood multidisciplinary interventions.

The most prominent considerations derived from the studies collected for this review included being aware of user/practitioner bias, referring to proposed methodological recommendations to ensure good reliability and validity, considering the combined use of GAS with standardized measures or frameworks, and adopting a collaborative and SMART goal setting approach. Most of the articles within this review were categorized as having low to moderate methodological quality in accordance with Melnyk and Fineout-Overholt’s (2015) levels of evidence hierarchy. Consistent with the conclusions presented by Harpster et al. (2018), the mix of methodological designs indicate that users/practitioners and researchers/program evaluators should adopt a more rigorous and standardized approach when applying GAS methodology. As evident throughout the available literature, the most significant limitation of GAS is its dependence on its users and their ability to generate unbiased, SMART, valid, and reliable 5-point scales that are meaningful to the client and family. Some recommendations found in this review to help ameliorate this limitation included the combined use of GAS with a standardized outcome measure or frame-

<table>
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<tr>
<th>Study</th>
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<th>Population</th>
<th>Design</th>
<th>Results</th>
<th>Conclusion of Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calder et al., 2018</td>
<td>Early childhood multidisciplinary intervention services</td>
<td>10 studies met the inclusion criteria</td>
<td>Systematic review</td>
<td>GAS was 1 of 8 outcome measures recommended in literature</td>
<td>GAS has moderate to strong robustness; is multidimensional and clinically useful in documenting change over time</td>
</tr>
<tr>
<td>Chiarello et al., 2016</td>
<td>School-based physical therapy</td>
<td>296 students with CP, down syndrome, DD, 109 PTs</td>
<td>Longitudinal pre/post design</td>
<td>Students established/achieved meaningful PT goals using GAS</td>
<td>GAS is useful for progress monitoring and documentation of outcomes</td>
</tr>
<tr>
<td>Keenan et al., 2013</td>
<td>Life skills coaching</td>
<td>50 children/youth with CP, spina bifida, ABI, ASD</td>
<td>Retrospective study</td>
<td>Goal attainment was statistically/clinically significant for all interventions</td>
<td>Goal-focused life skills coaching is effective in supporting life skill development for youth with disabilities</td>
</tr>
<tr>
<td>King et al., 2000b</td>
<td>School-based multidisciplinary therapy services</td>
<td>16 students with AD, DCD, CP, along with their parents and teachers</td>
<td>Longitudinal pre/post design</td>
<td>Majority of children showed expected or greater than expected improvement on functional goals</td>
<td>GAS is suitable for evaluating treatment outcomes for children receiving school-based therapy services</td>
</tr>
</tbody>
</table>

Abbreviations: GAS, Goal Attainment Scaling; CP, Cerebral Palsy; FMD, Fine Motor Difficulties; ABI, Acquired Brain Injury; ASD, Autism Spectrum Disorder; DD, Developmental Delay; PTs, Physical Therapists; AD, Articulation Difficulties; DCD, Developmental Coordination Disorder

Discussion

Table 3. Recent Uses of Goal Attainment Scaling (GAS) in Alternative Settings
work when developing and rating scales (King et al., 2000a; Keenan et al., 2014; McDougall & Wright, 2007; Law et al., 2004; Turner-Stokes, 2009), using multiple and/or separate raters when setting and evaluating goals (Keenan et al., 2014; King et al., 2000a; King et al., 2000b; McDougall & King, 2007; Maillioux et al., 2007), using predetermined “item-banks” for commonly identified goals to increase generalizability (Krasny-Pacini et al., 2013; McDougall & Wright, 2007; Tennant, 2007), relying on formal resource guides and their procedures (King et al., 2000a; King et al., 2000b), being precise when developing the five levels of goal attainment (King et al., 2000a; McDougall & King, 2007), and receiving formal training in the tool’s use (Calder et al., 2018; Harpster et al., 2018; McDougall & King, 2007; Steenbeek et al., 2007; Tennant, 2007).

While the recommendations proposed in the existing literature aim to improve the overall reliability and validity of GAS scales, the evidence is mixed on whether all these recommendations would be applicable or appropriate if used in actual clinical practice. For example, while many studies suggested the use of different practitioners when it comes to setting a goal, providing an intervention, and then rating the client’s changes in performance, McDougall and King (2007) stated that it is more realistic and cost effective for the treating practitioner to be involved in the goal setting process. Another example is the use of predetermined item-banks, or commonly identified goals, to help with generalizability, as this recommendation may defeat the purpose of using an individualized outcome measurement tool (McDougall & Wright, 2009). Overall, the findings from this literature review indicate that while GAS has proven to be a flexible and collaborative evaluation tool that is frequently used in pediatric rehabilitation, the current research suggests that users/practitioners need to be aware of the tool’s limitations, as well as consider some of the proposed recommendations to ensure robust, valid, and reliable scale construction (Harpster et al., 2018; Krasny-Pacini et al., 2013).

In relating the findings gathered from this literature review back to Bandura’s Social Cognitive Theory (1997), Locke and Latham’s Goal-Setting Theory (2002), and the ICF-CY (World Health Organization, 2007), GAS provides a collaborative, biopsychosocial, and patient- and family-centered approach to goal setting. This means that goals should be created to reflect what is most important in the client’s and family’s life and should resonate with any of the domains embedded in the ICF-CY framework (Krasny-Pacini et al., 2013; McDougall & Wright, 2009). While practitioners tend to focus on impairment-based goals, clients and families typically focus on achieving goals that are consistent with the activity and participation domains (McDougall & Wright, 2009; Rosenbaum & Stewart, 2004). Therefore, by involving and valuing the client and family in the goal-setting process, some potential advantages of using GAS could include increased client and family satisfaction; increased client motivation toward goal attainment; increased content validity; as well as the establishment of realistic client, family, and practitioner expectations about treatment planning (McDougall & King, 2007; Miller et al., 2007).

Implications

GAS is an individualized outcome measure designed to not only monitor or evaluate change over time for individual clients, but it can also be used to evaluate the effectiveness of interventions, services, and programs (McDougall & King, 2007). GAS is frequently used in pediatric rehabilitation settings by multidisciplinary practitioners, as it can be applied to a variety of interventions, ages, and diagnoses; however, its “success depends upon formulating unambiguous goals and methods… it is flexible to cover most situations, it is patient-specific, and can be easily taught and used by the whole team” (Bovend’Eerdt et al., 2009, p. 359; Donnelly & Carswell, 2002; Harpster et al., 2018; Mertens & Wilson, 2012). The primary benefit of using GAS is rooted in its collaborative nature and its ability to measure clinically significant change in individual performance and goal attainment (King et al., 2000a). This is different from standardized measures, as they typically rely on generic scales that may not capture meaningful and relevant outcomes that are important to the client or family (Krasny-Pacini et al., 2013). Therefore, as GAS uses a biopsychosocial and patient- and family-centered approach to goal setting, its methodology is unique and appealing to practitioners working in pediatric rehabilitation settings (Bovend’Eerdt et al., 2009; King et al., 2000a; Maillioux et al., 2007).

Implications from the literature review findings indicate the need for more rigorous and standardized applications of GAS methodology, as well as the need for more robust study designs moving forward. In
terms of implications for research and training and to allow for more accurate applications of GAS, future studies should also consider including descriptions of the specific and formal training that was implemented as part of their research. Prospective studies should continue to apply GAS to a variety of diagnoses, age groups, and disciplines, such as the child life specialty, as this methodology is in keeping with patient- and family-centered care approaches valued by the profession (Scobbie et al., 2009; Steenbeek et al., 2007).

In terms of implications specific to child life practice, it is known that professionals today should be relying on current and relevant evidence-based research to provide high quality care to their clients (Bexelius et al., 2018). Considering many practitioners are already using GAS as a validated and individualized outcome measure, child life specialists should also strive to make high quality, relevant, and meaningful goals with their clients and families. More specifically, they should develop goals with clients and families in systematic ways that adhere to an overarching framework. This is especially true for child life specialists working with long-term clients or client populations that are already accustomed to using 5-point rating GAS scales with other members of the multidisciplinary health care team, such as children living with cerebral palsy who are accustomed to setting physiotherapy GAS goals. Goals that are collaboratively set with clients, families, and child life specialists could focus on a myriad of interventions. For example, specific child life GAS goals could focus on improvements to a client’s coping and their ability to utilize coping strategies without assistance or even improvements to a client’s ability to express and communicate their emotions without assistance. Whenever a client is expected or anticipated to demonstrate a change in individual performance following a child life intervention or service, GAS could be implemented, as its 5-point rating scale could help target individual and unique intervention changes (Miller et al., 2007).

Should a child life specialist choose to utilize this tool in their daily practice, they would ultimately need to receive comprehensive training on the tool’s use and be made aware of the common errors and biases associated with GAS methodology (McDougall & King, 2007; Turner-Stokes, 2009). This is important, as new users need to ensure that they are applying the tool reliably, effectively, and with enough methodological rigor (King et al., 2000b; Steenbeek et al., 2007). In addition, as many practitioners outside of the child life profession are already utilizing this methodology in their daily practice, child life specialists could also take the opportunity to observe and collaborate with these allied health professionals in order to thoroughly understand the tool’s practical and wide applications. This collaboration could potentially enhance communication among the multidisciplinary health care team by encouraging the development and/or expansion of shared goals, as well as the establishment and awareness of clear roles and allocation of responsibilities. Not only would the adoption of GAS methodology be consistent with collaborative and patient- and family-centered care approaches, it could also provide a means to evaluate child life interventions, as well as the program itself (Wilson & Cross, 2009). For example, GAS could be used to ensure that a child life specialist’s goals for interventions are congruent with the overall goals, missions, and values held by their program (Wilson & Cross, 2009). As stated by Wilson and Cross (2009), while “the attributes of child life programs vary, the most crucial elements remain constant: to ensure quality services to patients and families, and to maintain professional competency and consistency of programming” (p. 218). Therefore, it is evident that GAS would likely be both compatible and complementary with the daily practices of child life specialists.

**Conclusion**

When providing rehabilitation interventions and services to individual clients and families, health care practitioners should rely on the knowledge and unique perspectives held by their clients and families to inform the setting of clear, meaningful, and relevant goals. Considering that goals have the ability to enhance an individual’s competence, motivation, and participation, as well as improve their functional outcomes, it is not surprising that goal setting has become a core process in pediatric rehabilitation (McDougall & King, 2007; Øien et al., 2010; Turner-Stokes, 2009). What is so unique about GAS and its collaborative approach to the setting and rating of individual client goals is its ability to include and evaluate the outcomes that are most important to each client in the context of their own life (Steenbeek et al., 2007; Turner-Stokes, 2009). As there is so much variation in the way child life specialists set goals and implement their interventions and services, they should consis-
tently utilize individualized outcome measures such as GAS in their daily clinical practices, as they have the ability to target the unique goals and perspectives held by clients, families, and practitioners.

By specifically examining the current applications, advantages, and psychometric properties of GAS used in pediatric rehabilitation, this paper argues that GAS could and should be integrated into child life practice, not only for the evaluation of client’s progress towards meeting goals, but also for assessment of the effectiveness of child life interventions, services, and programs. According to Hollon and Skinner (2009), “the success of child life work is dependent on the accurate and ongoing assessment of a child and [their] family as they experience and respond to health care encounters” (p. 116). Based on the information gathered from the studies included in this review and the recommendations provided for the potential transferability of GAS into child life practice, this outcome measurement tool would likely be effective for child life specialists working in pediatric rehabilitation settings, as it can help them create more personalized care plans for clients and families.
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