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# Attitudes towards child life specialists and their utilization within pediatric urology

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**Introduction:** The American Academy of Pediatrics views Certified Child Life Specialists (CCLS) as "an important component of pediatric hospital based care to address the psychosocial concerns that accompany hospitalization." CCLSs help patients and parents navigate the complex medical system in order to minimize psychosocial and emotional stress by implementing age appropriate coping skills. This survey explores the perceptions towards CCLS and their utilization with pediatric urology.

**Materials and methods:** A Survey Monkey questionnaire was developed and distributed to Society for Pediatric Urology members (SPU) (n = 314). Providers were queried about CCLS implementation and their perception regarding CCLS's role in improving health related quality of life (HRQOL).

**Results:** There was a 34.1% response rate (n = 107). Ninety-four providers (87.9%) reported CCLS interaction with their patients and greater than 95% of providers felt CCLS imparted some degree of benefit to their patients' HRQOL. Only 4.7% felt CCLS offered no benefit to the patients. CCLS were consistently used in a minority of inpatient and outpatient settings and never in the radiological setting. They were used at least 50% of the time by the most responders in inpatient and radiological setting and nearly the same in the ambulatory surgery setting.

**Conclusions:** This survey illuminates that the majority of providers interact with CCLS in clinical settings and believe their involvement is beneficial. However, CCLSs are under-utilized during invasive urological procedures where patient anxiety is high. By understanding perceptions of providers and their practice patterns we can overcome barriers to CCLS use and improve their quality of life.

**Key Words:** pediatric urology, quality of life, clinical practice patterns, child life, certified child life specialists

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## Introduction

Strategies for alleviating anxiety during medical procedures, especially within the pediatric population, have continued to pose a challenge for physicians and healthcare staff. Since the early 1920s, ancillary medical staff that serve to provide support, sensory stimulation, and comfort have been incorporated in the treatment of pediatric patients.<sup>1</sup> The first child life programs were developed in the 1950s and encompassed the educational, developmental, and

psychosocial needs of hospitalized children.<sup>2</sup> However, despite these changes, many problems were still not adequately addressed due to the limited scope of their practice.

As this field evolved, Certified Child Life Specialists (CCLSs) became more integrated in the healthcare team and worked tirelessly to develop an environment that would reflect the needs of both children and their families. It grew into a profession that required a formal degree and advanced certification in order to participate in patient care.<sup>3</sup> The CCLS program is a unique undertaking utilized by the pediatric medical community to help patients cope with the stress of medical conditions, radiological studies, surgical procedures and hospital admissions in order to improve Health Related Quality of Life (HRQOL).<sup>4</sup> Given that children respond to medical experiences in a unique manner compared to adults, the role of the CCLS should be focused on assessing the needs of every child and family, as well as providing the appropriate interventions.<sup>5</sup> Moreover, in a 2014 policy statement

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TABLE 1. Survey questions

Do you have Certified Child Life Specialists interact with your patients at your institution?	
If yes, for inpatient admissions?	Every time? More than half?
If yes, for ambulatory surgery?	Half? Less than half?
If yes, for outpatient radiologic testing?	Very little? Never?
How much do Certified Child Life Specialists help improve the HRQOL of your patients?	

from the American Academy of Pediatrics, CCLSs were described as “an important component of pediatric hospitalization to address the psychosocial concerns that accompany hospitalization and other healthcare experiences.”<sup>6</sup> Consequently, the role of CCLSs as providers who are an integral part of the healthcare team has continued to expand.

Most hospitals that offer care to pediatric patients have child life programs and employ the use of CCLSs.<sup>2</sup> There are over 400 child life programs in Canada and the United States, and there is an abundance of literature highlighting their advantages in fields such as radiology, general surgery, and anesthesia.<sup>7-10</sup> Despite this growing use, we have a limited understanding of how CCLS are perceived by pediatric urologists and how they are utilized in the pediatric urology community. Therefore, we sought to further explore the current attitudes of pediatric urologists towards CCLS and gauge the level of interaction CCLS have with patients in various health care settings. More specifically, we aimed to determine: 1) if pediatric urologists implement the use of CCLSs in practice, 2) if pediatric urologists feel that CCLS are useful, and 3) where are CCLSs most utilized. We believe that CCLS are perceived to be of utmost importance to the psychological well-being of patients during inpatient and outpatient care yet are under-utilized across these settings.

## Materials and methods

A SurveyMonkey (SurveyMonkey Inc, Palo Alto, CA, USA) 5-item questionnaire was developed to examine how pediatric urologists believe CCLSs are currently being utilized and their perceived effects on HRQOL surveys, Table 1. Following approval from our internal Institutional Review Board, the questionnaire was sent electronically to all members of the Society for Pediatric Urology (SPU) (n = 314). Participation was encouraged through the use of several follow up reminder e-mails. Providers were queried regarding the frequency of CCLS utilization in various treatment settings, including inpatient, ambulatory surgery, and outpatient radiological procedures. Survey results were analyzed using descriptive statistics.

## Results

Of the 314 pediatric urologists who were sent the survey, 118 (37.8%) responded to the survey and 107 of the 118 (90.7%) respondents completed the full survey. Ninety-four of 107 providers (87.9%) reported having CCLSs interact with their patients while 13 (12.1%) reported no interaction, Table 2. In the inpatient setting, 32 responders (33.7%) reported that CCLSs interact with the patient every time, 25 responders

TABLE 2. Questionnaire results of Certified Child Life Specialists utilization

	<b>In-patient admission</b>	<b>Ambulatory surgery</b>	<b>Out-patient imaging</b>
All the time	33.7%	22.1%	0
> 50%	26.3%	23.2%	63.8%
< 50%	36.8%	47.4%	26.6%
Never	3.2%	7.4%	9.6%

(26.3%) reported interaction more than half of the time, 35 responders (36.8%) reported half or less than half, and 3 responders (3.2%) reported never using the services of CCLSs. In the ambulatory surgery setting, 21 providers (22.1%) reported using CCLSs every time, 22 providers (23.2%) reported use more than half of the time, 45 providers (47.4%) reported CCLS use half or less than half of the time, and 7 providers (7.4%) reported never employing the services of CCLSs in this setting. Finally, in the outpatient radiologic testing setting (e.g. voiding cystourethrography), 16 providers (17%) reported CCLS use every time, 27 providers (28.7%) reported use more than half the time, 17 providers (18.1%) reported CCLS involvement half the time, 25 providers (26.6%) reported interactions less than half of the time and 9 providers (9.6%) reported never utilizing the services in this setting.

Lastly, the questionnaire asked providers to which degree they thought CCLSs helped improve the HRQOL of their patients. Greater than 95% of providers felt CCLSs imparted at least some degree of benefit to their patients' HRQOL and only 5 (4.7%) felt that employing CCLSs did not help at all.

## Discussion

CCLSs have become increasingly utilized in healthcare, and particularly more so during invasive procedure-based interactions. Pediatric urological conditions are unique in the requirement of exposure of intimate anatomy and repeated evaluation of genitalia and "embarrassing" procedures such as voiding cystourethrograms (VCUGs) which require voiding in front of strangers. These situations during the formative years may cause lasting psychological distress depending on the procedure and the specific age group undergoing treatment. However, a CCLS's specific knowledge of child development can incorporate age appropriate coping skills to facilitate discussion between healthcare providers, parents and their children about what to expect and what concerns they might have and mechanisms to lessen anxiety.<sup>11</sup> Therefore, we surveyed pediatric urologists to determine: 1) how pediatric urologists characterize the overall implementation of CCLSs in practice, 2) if pediatric urologists feel that CCLS are useful, and 3) in which settings they think CCLSs are most utilized. Of the practitioners who completed the questionnaire, 33.7% reported using CCLSs every time in the inpatient setting, 22.1% reported using CCLSs every time in the ambulatory surgery setting, and 63.8% reported using CCLSs at least half of the time in the outpatient radiologic testing setting. In addition, more than 95% of providers felt that

CCLSs offered positive contribution to their patients' HRQOL. There is an obvious need for more consistent use of CCLSs by pediatric urologists as the variety of conditions treated necessitates multiple invasive tests, studies, and procedures and is echoed by the high rate of benefit perceived by the providers. The importance of CCLS input should also be stressed to pediatric urologists who responded that they are never used. The question arises of whether services are not utilized due to lack of availability or lack of knowledge of the degree to which CCLS can improve care.

Our findings mirror that of other studies that highlight the utility of CCLSs. Stressful medical procedures can have lasting physical and psychosocial consequences on children and result in post-traumatic stress reactions and avoidance of healthcare in adulthood; however, CCLSs can help mitigate these negative interactions.<sup>11</sup> In a prospective assessment of the impact of CCLSs on parents and children in a pediatric imaging department, Tyson et al noted significant improvement in parent satisfaction and lower perception of their child's pain and distress when a CCLS was involved in care compared to when a CCLS was not involved.<sup>4</sup> Furthermore, children who interacted with a CCLS demonstrated greater cooperation, a lower perception of pain and distress, less fear, and a better overall experience. Sorensen et al established that the use of CCLSs assisted with preparation for surgical cases by helping the patient and parents become more comfortable with the process thus combating unfamiliar circumstances.<sup>12</sup> In the outpatient setting, CCLS implementation can be used to decrease the amount of sedation necessary during VCUGs.<sup>13</sup> Thacker et al demonstrated that the test points of highest anxiety were during catheter placement and the full bladder portion of exam and that with use of CCLSs their overall distress scores were much less than previously seen in the literature.<sup>13</sup>

As previously mentioned, our pediatric medical center mandates the use of CCLSs in the inpatient setting (i.e. pyeloplasty, ureteral reimplantation), which can be implemented across all centers. Applying the same requirement to the ambulatory and outpatient settings can also be considered with minimal disruption of productivity. In fact, application of CCLS services to the ambulatory setting can potentially decrease the need for pre-sedation and excess analgesics for routine outpatient procedures such as circumcisions and hypospadias repairs. Durand et al. implemented mandatory child life consultation during the scheduling of pediatric magnetic resonance imaging (MRI) for children between 5 and 18 years old to examine its effects on workflow and impact on general anesthesia (GA) use.<sup>14</sup> The authors determined that overall use of GA dropped significantly

from 23% to 19%, and use of GA declined from 45% to 35% for children between 5 and 10 years old. This study highlights the findings observed in our study where utilization of CCLSs and their resources offered options that would have otherwise been unavailable. Very few studies exist examining the exact cost-benefit analysis of CCLS. However, one retrospective study demonstrated that CCLS implementation in a radiation oncology practice resulted in an over 16% absolute reduction in anesthesia usage.<sup>15</sup> Such a reduction in GA meant that CCLS decreased costs by over \$775,000 for every 100 children treated every year between the ages of 3-12 years of age while the cost of the average CCLS is approximately \$50,000.<sup>15</sup> Another study directly examined the cost reduction when children required partial rather than full sedation with the addition of child life services while undergoing daily anesthesia for brain tumors at a pediatric radiation oncology center and calculated potential health care costs savings of \$77,814 over 116 patients.<sup>16</sup> These cost-benefit analyses support the necessity of CCLS in tertiary-care pediatric hospitals where the reduction in anesthesia would help offset the cost of CCLS several times over in addition to the potential decrease in neurotoxic effects of GA.

This study has several limitations. The questionnaire utilized was not a validated survey, which does not allow us to correlate our findings with other commonly used surveys. In addition, our sample size was small and we had a low response rate in relation to the number of pediatric urologists who received the survey. This prevents us from generalizing our results to the population. In addition, our results are potentially biased if those providers who do not believe CCLS render a vital service to the healthcare team refrained from completing the survey or vice versa with providers with access to CCLS more likely to respond with favorable answers. The practice type of the physicians as well as geographic distribution was also not elicited.

Furthermore, we did not objectively measure satisfaction and impact from the perspective of patients or parents. However, we feel that the results from the present study are encouraging, as they offer insight into the utility of CCLS in the pediatric urology setting.

## Conclusion

CCLSs are increasingly being utilized and have demonstrated a positive impact in the care of pediatric patients. There is a considerable amount of literature demonstrating the benefit of CCLSs in various medical specialties, however, their usage in the pediatric urology setting is poorly understood. As physicians we recognize the importance of CCLSs and as the

role of CCLSs continues to expand, they will become more important in identifying patients or families who may be vulnerable and unable to cope with the high levels of stress that urological procedures may cause. Understanding the attitudes and perceptions of pediatric urologists towards CCLSs and their roles in patient care can help identify barriers to access and encourage more standardized inclusion of services within set pathways in the inpatient, ambulatory and radiological settings. Future research should also focus on patient outcomes and satisfaction after pediatric urological procedures following the implementation of CCLSs as well as their impact on patient's HRQOL specifically aimed at the pediatric urologic population. □

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