The Impact of Provider Education on Pediatric Palliative Care Referral

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Abstract

Introduction: Palliative care can significantly benefit children managing a life-limiting illness; unfortunately, services are generally reserved for end of life. The aim of this project was to demonstrate how established guidelines coupled with provider education could impact referrals.

Methods: Educational sessions developed using information processing theory and outlining referral recommendations were offered to providers in the NICU, PICU, and Center for Cancer and Blood Disorders at a tertiary care facility. Presurveys and postsurveys were administered at the time of the intervention and referral numbers for the organization were collected for two months prior and two months following.

Results: Descriptive statistics and paired t-tests were used to compare survey data and referral rates.

Discussion: Palliative care is imperative for meeting patient goals and optimizing quality of life. Provider knowledge of referral criteria ensures that patients receive this service early in their disease trajectory and can benefit from its inclusion within their care team.

The Impact of Provider Education on Pediatric Palliative Care Referral

Managing care for children with life-limiting illnesses is a complex and multifactorial process that requires the collaboration of healthcare providers and multiple interprofessional services to provide optimal care for the patient and family. Palliative care is a specific pediatric subspecialty whose main goals are to relieve suffering, improve quality of life for both patients and families, facilitate informed decision-making conversations, and provide care coordination for children living with a life-limiting illness (American Academy of Pediatrics [AAP], 2013). Not only is the provision of these services essential but also including palliative care early in the disease trajectory ensures optimal patient and family outcomes (Zhukovsky, Herzog, Kaur, Palmer, and Bruera, 2009). The Centers for Disease Control and Prevention most recent data on vital statistics reported 41,881 deaths in children between the ages of zero to nineteen in 2015 (Kochanek, Murphy, Xu, Tejada-Vera, 2016). Of those 23,215 were children under the age of one and 18,666 were children between the ages of one and nineteen (Kochanek et al., 2016). While, the majority of these fatalities were the result of accidents, homicide, or suicide; a significant number were from other causes such as malignancies, chromosomal abnormalities, congenital malformations, and heart disease. These other causes of fatalities represent a population of patients who could benefit from the early incorporation of a palliative care team. The AAP recognizes the importance of pediatric palliative care and the desperate need for timely referral. The most recent policy statement released by the organization included definitions for core commitments for pediatric palliative care were defined. These included, the importance of integrating a dedicated care team to help navigate complex decisionmaking and provide social and spiritual support services early in the continuum of care (AAP, 2013). Furthermore, the AAP (2013) explicitly states that referral to palliative care providers can occur at any point in the disease process, including at diagnosis, and should be used throughout the course of the illness to support the goals of care. These services should not be restricted to terminal patients, but rather should supplement care even when goals are still focused on curative treatments (AAP, 2013). The magnitude of these recommendations will undeniably be difficult to implement and will require a massive overhaul in the way children living with these chronic conditions are managed; however, the short and long-term benefits these families will see is irrefutable.

The project site is a freestanding children's hospital with 490-licensed beds was utilized as the project site. The palliative care department at this facility has automatic referral systems in place for children undergoing hematopoietic stem cell transplant and heart transplant. However, like most major children's hospitals and palliative care programs, the department has difficulty capturing patients with life-limiting illnesses earlier in their disease trajectory to be able to provide more comprehensive services.

To develop an effective solution, a literature review was conducted using the PICOT question: In pediatric patients with a life-threatening illness, how does a standardized approach as compared to usual care impact early referral to palliative care? Databases searched included: CINAHL, PubMed, Cochrane Library, and PsycINFO. Given the paucity of information pertaining to this particular population, adult literature was also searched for information relative to the topic. Keywords used in these searches included: pediatric, pediatric OR children, palliative care, palliative care OR end of life, palliative care referral, referral, necessity of referral, outcomes, referral criteria OR standard approach, early referral OR timing of referral, timing of referral OR early referral OR referral, standard OR criteria OR guideline. Results were limited to those in the English language and performed in humans. All reference lists of relevant articles were also reviewed. This search resulted in ten high quality articles that were included for synthesis. These articles were then graded using the Melnyk and Fineout-Overholt (2015) criteria for hierarchy of evidence and included in the results was one level VI study, four level V studies, and five level IV studies. Most of the studies were qualitative in nature, owing likely in part to the sensitivity of the subject matter.

Multiple interventions for palliative care referral were examined across studies, including: staff education and training, the formation of a dedicated palliative care team, the development of guidelines or criteria for referral, procedures to increase awareness of palliative care services, automatic referrals, routine symptom screening and assessment, and family request. Most of the studies used a combination of these methods to achieve early referral. The most common method demonstrated for efficacy throughout the evidence, however, was the development of standardized guidelines or institutional criteria in conjunction with provider and staff education on how to utilize these tools and the importance of early palliative care referral.

Based on a review of the literature, a project was developed to create standardized referral criteria and subsequently providing staff education. Cognitive learning theory served as the foundation for the project and the development of the intervention. Cognitive learning theory is the interaction of perception, thought, reasoning, memory, development, and processing of information within the learner (Butts & Rich, 2015). The theory is founded on five working stages of learning: the attention stage, the sensory memory stage, short-term or working memory stage, long-term memory stage, and the information retrieval stage; all of which were incorporated while developing the intervention. Furthermore, The Iowa Model for Evidence-Based Practice guided this project because it was created specifically for practitioners to implement a practice change. This model assumes a team effort, a dedication to process rather than an event, and includes evaluation as a crucial component of implementation (Rycroft-

Malone & Bucknall, 2010). This model also provides a framework for improving patient outcomes and nursing practice, while simultaneously monitoring for cost containment (Taylor-Piliae, 1999). Using the evidence, cognitive learning theory, and the Iowa Model for Evidence-Based Practice it was concluded that the ultimate aim of this project was to demonstrate how established guidelines coupled with provider education could impact referral rates.

Methods

Design

Educational sessions were developed using information processing theory, which outlined referral recommendations from the AAP, National Hospice and Palliative Care Organization (NHPCO), and those included in the institutional policy. Presurveys and postsurveys validated by two clinical experts in the field were administered to participants at the time of the intervention. Referral rates for the organization were also collected for two months prior to the intervention, and two months following the intervention.

Setting

This project was completed at a large, freestanding pediatric institution in Dallas, Texas. Participants were recruited through flyers and department educators to attend a short informational session, each held twice a day for one week, in the Neonatal Intensive Care Unit (NICU), Pediatric Intensive Care Unit (PICU), and Center for Cancer and Blood Disorders (CCBD). The presentation was also given at a monthly meeting of Advanced Practice Providers.

Sample

Institutional Review Board (IRB) approval was obtained through the author’s affiliated university prior to the start of the project. All of the educational sessions were open to physicians, advanced practice providers, and registered nurses within the organization. Each participant who attended an educational session was given a copy of the consent form and completion of the presurvey and postsurvey served as their consent to participate in the project. Subjects were notified that participation was voluntary. They were invited to attend the presentation and informed that they could decline participation in the survey portion. All subjects were required to be 18 years of age or older to participate, and there were no known risk factors associated with the project.

Outcome Measures and Data Collection

Presurvey and Postsurvey

The presurvey and postsurveys were designed by the investigator in conjunction with stakeholders from the palliative care department. The presurvey collected demographic data including: role within the organization, number of years in current role, number of years within the institution, current department employer, comfortability with palliative care referral on a 6-point Likert scale, and an estimated number of personal palliative care referrals placed within the last year. The postsurvey first assessed knowledge acquisition of the material presented by posing four clinical questions related to the presentation. The postsurvey then reassessed comfortability in referring to palliative care on the same 6-point Likert scale and also asked participants to score the likelihood of placing a referral after listening to the presentation and how valuable they thought the information was to their personal practice. Finally, the postsurvey posed a qualitative question for participants asking what the biggest reason that affected their decision to postpone placing a palliative care referral or deciding not to refer at all.

Referral Rates

The director for palliative care obtained referral rates collected through the electronic medical record for the purposes of this project. Referral rates were collected for two months prior to the intervention and compared with two months postintervention.

Data Analysis

Statistical analyses were completed using Statistical Package for the Social Sciences (SPSS) version 25.0 software. Descriptive statistics were used to describe demographic variables and postsurvey knowledge based question scores. Comfortability scores in the pretest and posttest were analyzed using a paired t-test.

Results

Demographics

A total of 64 participants were recruited for the project and completed the questionnaires. Key sample demographics for the group are displayed in Table 1. The majority of the participants were advanced practice providers (57.8%; *n*= 37), followed by registered nurses (39.1%, *n*= 25), and physicians (3.1%, *n*= 2). Of those participants, department sites included the PICU (6.3%, *n*= 4), NICU (21.9%, *n*= 14), CCBD (26.6%, *n*= 17), and the majority from other departments within the hospital (42.2%, *n*= 27); two participants were employed in multiple departments (3.1%, *n*= 2). The majority of participants estimated that they had not made a palliative care referral in the past year (48.4%, *n*= 31).

Knowledge Based Questions

The project was based on cognitive learning theory. To assess adequate knowledge acquisition immediately following the presentation, four questions were posed to participants regarding the material presented. Overall, participants demonstrated a strong understanding of the recommendations and guidelines used within the organization (see Table 2 and Figure 1).

Comfortability

Participants were asked to rate their comfortability with placing a referral to palliative care using a Likert scale of 0 to 5 both before and after the intervention. Presurvey data was compared to postsurvey data and there was a statistically significant difference in comfortability scores (see Table 3 and Figure 2). Presurvey scores for participants who completed the entire survey ranged from zero (very uncomfortable) to five (very comfortable) ($n = 55$; $\mu = 3.45$). Postsurvey scores ranged from three to five among participants who completed the entire survey ($n = 55$; $\mu = 4.51$).

Referral Rates

Preintervention referral rates were collected for two months prior to the intervention and compared to postintervention referral rates in the two months following the intervention. Referral rates were collected for the PICU, NICU, CCBD, and hospital-wide. The number of referral rates varied between units, and while there was a clinically significant increase in the number of hospital wide referrals postintervention, it was not considered enough to be statistically significant (see Table 4 and Figure 3).

Value

In the postsurvey participants were asked to rank how valuable the information was to their personal practice and the likelihood of making a referral to palliative care based on the information provided from zero to five on Likert scale. Overall, participants did find the information to be valuable to their personal practice ($n = 55$; $\mu = 4.65$; $\sigma = 0.552$). When scoring likelihood of referring to palliative care, zero (not likely to refer at all) and five (very likely to refer). Overall, participants who answered the question rated that they were more likely to refer to palliative care based on the information provided (*n* = 54; $\mu = 4.52$; $\sigma = 0.666$).

Reasons for not referring

The final survey was: In your personal practice, what is the biggest reason you have postponed referral to palliative care or decided not to refer at all? Qualitative data was evaluated using grounded theory. The most common reasons given by participants included: "attending provider refused to make the referral," "parents requested providers not make a palliative care referral," "the provider did not know who qualified for a referral," and "the provider did not know how to place a palliative care referral."

Discussion

The aim of this project was to determine if standardized palliative care referral guidelines and an educational initiative coupled with those guidelines would have an impact on referrals within the department. Traditionally, children are not referred to palliative care until late in their disease trajectory, so it is important to identify ways in which providers may be able to identify them earlier. While this project did show that an educational initiative was effective in provider comfortability with referral, there was no statistically significant increase in the overall number of referrals the department received.

Referral Process

Presurvey and postsurvey scores demonstrated increased provider comfortability with the referral process; and the increase prior to and after the intervention was considered statistically significant. Furthermore, participants identified that they felt the informational sessions were valuable to their personal practice and that they were more likely to place a referral based on the information provided.

Referral Rates

Referral rates between the preintervention and postintervention period increased in the PICU, CCBD, and hospital-wide; however, they decreased in the NICU. While this increase in hospitalwide referrals is considered to be clinically significant, it was not considered statistically significant.

Clinical Practice and Research Implications

The results of this project were consistent with the evidence that standardized referral criteria and educational interventions are effective in impacting palliative care referrals. Within the institution, further methods of disseminating these guidelines to point of care providers continue to be implemented. For example, the presentation and accompanying materials have all been uploaded to the hospital’s web-based platform and educators throughout the institution have access to these materials so they can incorporate them in different unit-based educational initiatives.

Future initiatives include the potential of expanding this educational opportunity to more members of the various interprofessional teams present throughout the hospital. By reaching more members of the healthcare team, the number of referrals will continue to be impacted. Furthermore, some of the most common reasons given for not placing referrals included a lack of knowledge regarding who qualified and how to place a referral, and parent refusal. Future projects could explore the possibility of targeting these areas specifically with educational initiatives. Initiatives aimed towards giving providers the tools regarding how to approach families with this discussion could also impact referrals.

Limitations

There were several project limitations that warrant discussion. The most significant limitation was the small sample size. The low physician attendance was another significant limitation, especially because since qualitative data revealed that one of the most common reasons not to refer was related to physician refusal. By targeting this population and finding methods to reach more direct patient care providers, this project has the potential to be more impactful within the institution. It is possible that the format for holding these educational sessions was not convenient for the majority of providers. Future endeavors could explore using computer-based training or making educational sessions mandatory.

Another limitation of the project was the short time frame for data collection. It is possible that reviewing referral rates for a longer period of time preintervention and postintervention could potentially yield more statistically significant results.

Conclusion

Multiple national initiatives have called for system-wide changes to impact early palliative care referral and the benefits of involving this service early in the disease trajectory are undeniable for both patients and their families. While this project demonstrated that institutional guidelines and provider education are an effective method for impacting referrals, there is still more work to do. Pediatric palliative care is an essential service for children with chronic and life-limiting conditions. Considering the multiple national initiatives aimed at combating late referral, and the evidence supporting better patient outcomes, effective and functional models for impacting this process are needed for the field of palliative care to continue to grow and expand.

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Table 1. Demographics for Study Participants

Characteristic	**N**	**Percentage**
Professional Role		
Physician	2	3.1
Advanced Practice Provider	37	57.8
Registered Nurse	25	39.1
Number of Years Practiced in Current Role		
Less than 1 year	1	1.6
1 to 5 years	18	28.1
6 to 10 years	17	26.6
11 to 20 years	16	25.0
More than 20 years	12	18.8
Number of Years Practiced at this Institution		
Less than 1 year	4	6.3
1 to 5 years	21	32.8
6 to 10 years	14	21.9
11 to 20 years	20	31.3
More than 20 years	5	7.8
Department		
Pediatric Intensive Care Unit	4	6.3
Neonatal Intensive Care Unit	14	21.9
Center for Cancer and Blood Disorders	17	26.6
Other	27	42.2
Missing*	2	3.1
Self-Estimation of the Number of Referrals Placed in the Past Year		
0	31	48.4%
1 to 5	21	32.8%
6 to 10	10	15.6%
More than 10	1	1.6%
Missing	1	1.6%

* 2 participants were employed in multiple departments. Employee 1 was employed in the PICU and NICU and employee 2 held employment in the PICU and other.

Table 2. Knowledge Based Acquisition Questions

Question	**N**	**Percentage**
Question 1		
Correct	58	90.5
Incorrect	6	9.4
Question 2		
Correct	63	98.4
Incorrect	1	1.6
Question 3		
Correct	45	70.3
Incorrect	18	28.1
Missing	1	1.6
Question 4		
Correct	55	85.9
Incorrect	1	1.6
Missing	8	12.5

Figure 1. Knowledge Based Acquisition Questions

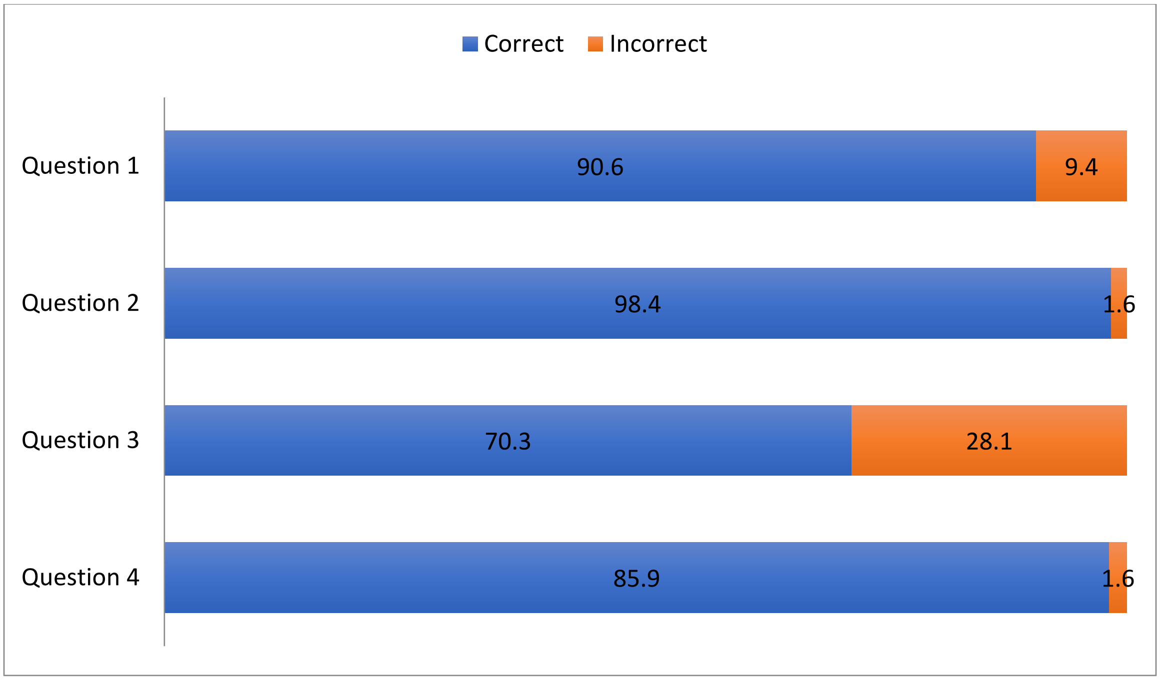

Table 3. Comfortability Scores

Paired Samples Statistics

	Mean	N	Std. Deviation
Pre-survey Comfortability in Referring to Palliative Care	3.45	55	1.358
Post-Survey Comfortability in Referring to Palliative Care	4.51	55	0.635

Paired Samples Correlation

	N	Correlation	Significance
Pre-survey Comfortability and Post-Survey Comfortability	55	0.436	<.01

Paired Samples T-Test

	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		t	df	Sig. (2-tailed)
				Lower	Upper			
Pre-survey Comfortability and Post-Survey Comfortability	-1.055	1.224	.165	-1.385	-.724	-6.392	54	<.01

Figure 2. Comfortability in Referring to Palliative Care

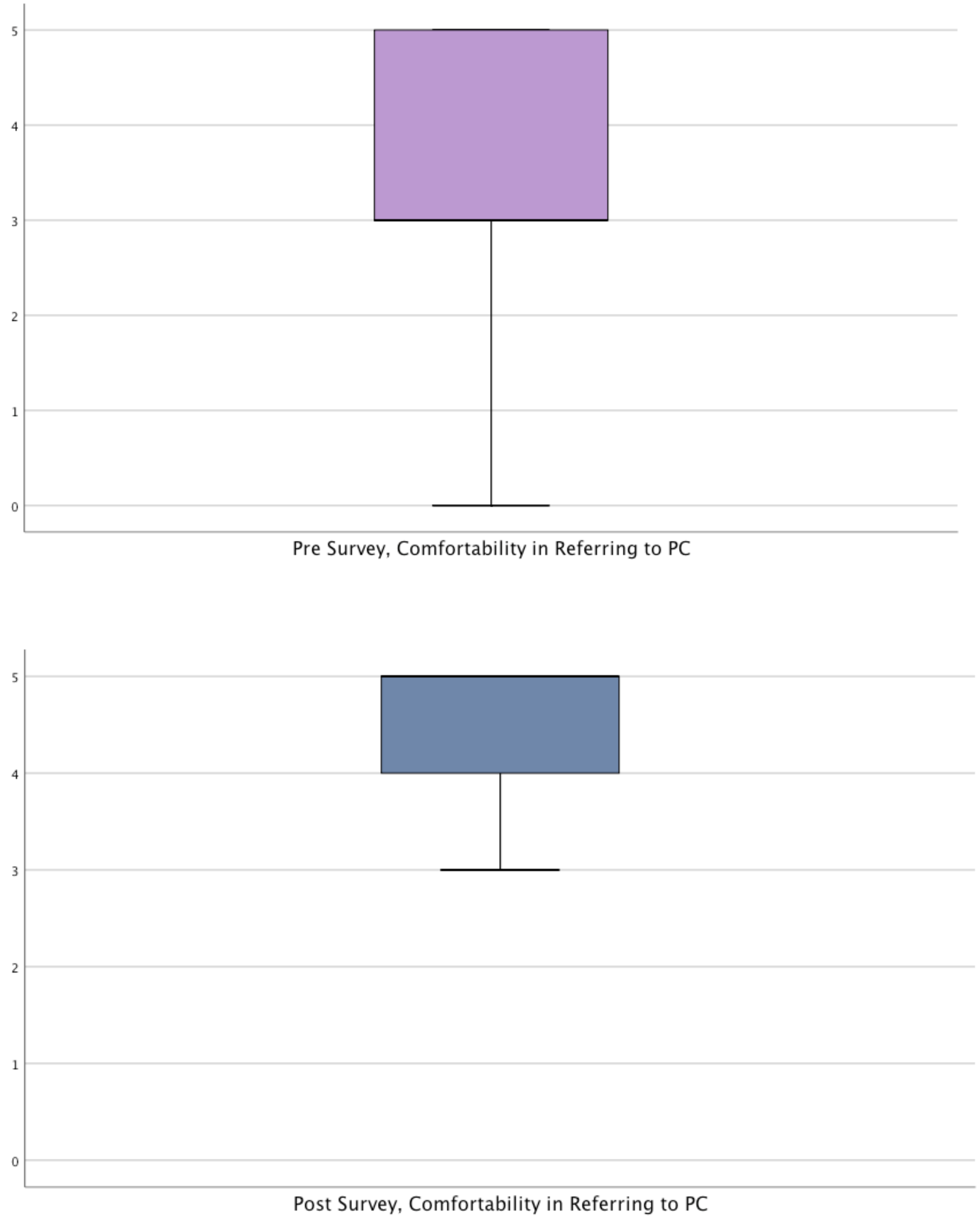

Table 4. Referral Rates

Group Statistics

	Pre or Post Intervention	N	Mean (per month)	Std. Deviation
PICU Referrals	Pre-Intervention	3	1.5	2.121
	Post-Intervention	12	6.0	1.414
NICU Referrals	Pre-Intervention	9	4.5	0.707
	Post-Intervention	6	3.0	1.414
CCBD Referrals	Pre-Intervention	4	2.0	0.000
	Post-Intervention	7	3.5	2.121
Hospital-Wide Referrals	Pre-Intervention	27	13.5	2.121
	Post-Intervention	44	22.0	5.657

Independent Samples Test

		t	df	t-test for Equality of Means			95% Confidence Interval of the Difference	
				Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
PICU Referrals	Equal Variances Assumed	-2.496	2	.130	-4.500	1.803	-12.257	3.257
	Equal Variances Not Assumed	-2.496	1.742	.148	-4.500	1.803	-13.467	4.467
NICU Referrals	Equal Variances Assumed	1.342	2	.312	1.500	1.118	-3.311	6.311
	Equal Variances Not Assumed	1.342	1.471	.350	1.500	1.118	-5.419	8.419

CCBD Referrals	Equal Variances Assumed	-1.000	2	.423	-1.500	1.500	-7.954	4.954
	Equal Variances Not Assumed	-1.000	1.000	.500	-1.500	1.500	-20.559	17.559
Hospital-wide Referrals	Equal Variances Assumed	-1.990	2	.185	-8.500	4.272	-26.881	9.881
	Equal Variances Not Assumed	-1.990	1.276	.252	-8.500	4.272	-41.589	24.589

Figure 3. Referral Rates Hospital-Wide