

REDUCE OVERFLOW INCONTINENCE TO PREVENT PRESSURE ULCERS IN
INDIVIDUALS WITH SPINA BIFIDA

A Doctor of Nursing Practice Project Report

by

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This Doctor of Nursing Practice Project Report meets the standards for scope and quality of
Texas A&M University-Corpus Christi and is hereby approved.

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DEDICATION

This Quality Improvement project is dedicated to my beloved mother. She believed in me from the time I came into this world. When the world would try to hold me back, she would remind me that the only person that can hold you back is you. She was my best friend and my sounding block when I would get frustrated and want to quit on something. We recently lost her in February just short of the completion of the ultimate goal we have been striving for. While she is not here with me now, I know she is smiling ear to ear seeing me complete this. Thank you for the love and support mom and I could not have done this without you. I love you!

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Thanks also go to my friends and family for the support and understanding during this long journey. I have had to make decisions to focus on my project and not to spend time with each of you. Thank you for everyone who prayed for this day, brought me food, and came over to play with my dog so I could focus on school once again, Thank You. I want to thank my amazing fiancé for your support and love through this process. Your patience and understanding has been unbelievable. A special thank you to my amazing father who always has a smile and positive comment for me when I was in need. Thank you for keeping my four-legged child and spoiling her. Most importantly thank you for all the years of reminders that you and mom gave me that “I was someone special and no one can change that or take it away” and giving me comfort when you would tell me “Baby, we will figure it out as long as it is what will make you happy”.

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ABSTRACT

Overflow incontinence has been directly linked to the development of pressure ulcers in individuals with Spina Bifida (SB). The implementation of a bladder diary and educational session to increase awareness of pressure ulcers and decrease overflow incontinence episodes was selected. This Quality Improvement (QI) project was a quasi-experimental design with pre-/post-intervention evaluation. The setting was Camp That Love Built summer camp at Camp For All in Burton, Texas. The participants included 45 campers with SB, five to 60 years old and 16 staff members. Eligibility was dependent on necessity for intermittent catheterization and attendance of camp for the entire week. All participants received an educational session focused on pressure ulcer prevention. Campers were given a bladder diary to document catheterizations and to assist with adherence to a prescribed catheterization schedule. Staff provided verbal reminders to campers to perform catheterizations. The measurement tools included PUKAT 2.0 pre- and post-test, PUAS, and a bladder diary. PUKAT results yielded score increase more than 10% in 35 of the 61 participants. Overflow episodes recorded on the bladder diary decreased by 81% from 37 episodes on day two to seven episodes on day five. PUAS scores increased 2% from pre- to post- intervention. Educational sessions and implementation of a bladder diary decreased the episodes of urinary incontinence.

Keywords: Spina Bifida, Pressure Ulcer, Bladder Diary, Incontinence

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PROJECT REPORT

Introduction

Spina Bifida (SB) is a permanent disabling birth defect affecting the spinal cord (American Association of Neurological Surgeons, 2017), resulting in varied levels of disability including bowel and bladder incontinence, wheelchair dependence, and poor sensation in the lower extremities and pelvic region. All these problems contribute to increased risk of pressure ulcers for people with SB (34%). Pressure ulcers are defined as an area of localized skin breakdown in an area of greater bony prominence including buttocks, heels, and hips (Chou et al., 2013). Ottolini et al. (2013) examined people across the life span with a variety of neurological defects and reported 260 of 276 pressure ulcers identified developed in outpatient settings. Individuals with SB had a pressure ulcer rate of 29% in children ages 2-10, 42% in children ages 10-20, and 55% in individuals >20 years of age between 2009 and 2012 (Kim et al., 2015).

As individuals with SB are experiencing a longer life expectancy, their care must not focus exclusively on disease management, but also on prevention of complications. Increased life expectancy of individuals with SB is another aspect revealing gaps in research and clinical guidelines for addressing prevention of pressure ulcers in this vulnerable population, with significant cost implications. The cost of caring for a pressure ulcer in the U. S. is \$20,900 to \$151,700, as reported by the Agency for Healthcare Research and Quality (AHRQ, 2014). If the rate of pressure ulcer development is between 30 – 50% in the estimated 70,000 people living in

the United States with SB (American Association of Neurological Surgeons, 2017), costs could potentially reach \$3.5 billion for management of a preventable problem.

This Quality Improvement (QI) project focused on the use of a bladder diary along with educating campers and staff on prevention of pressure ulcers. Reduction of urinary incontinence episodes can reduce overall risk of pressure ulcer development. Camp That Love Built (CTLB) is a one-week summer fully accessible camp specially designed for disabled persons sponsored by Spina Bifida Houston Gulf Coast (SBHGC) and served as the setting for this project. The mission of the camp is “to promote independence and growth of individuals with SB, through encouragement, education, and fun activities” (SBGHC, 2018).

Individuals with SB are not always capable of detecting when they have wet undergarments, leaving parents concerned about allowing them to participate in activities longer than a day trip (Fischer, Church, Lyons, & McPherson, 2015). Currently there is no process in place to specifically address bladder care at CTLB. This project used an educational session for campers and camp staff to implement a plan for pressure ulcer prevention, including a bladder diary to assist campers to accomplish timely completion of bladder care (urinary catheterization) with a goal of remaining dry between catheterizations. The number of catheterizations and wet undergarments on day one of camp, on the last full day of camp and during the one-week camp were measured. Each day was measured independently to evaluate trend. In addition, staff and camper knowledge and attitude regarding pressure ulcer prevention in individuals with SB were measured pre- and post- intervention. The goal was to reduce the number of wet undergarments to reduce the risk of pressure ulcers secondary to incontinence in individuals with SB attending a camp, away from usual caregivers.

Individuals with SB who have a pressure ulcer experience have an estimated 10.7 times greater risk of death compared to individuals with SB who do not have a pressure ulcer (Cai et al., 2016). If greater progress is not made in decreasing the risk of developing pressure ulcers related to urinary incontinence, individuals with SB will continue to die from a preventable cause. The purpose of this project was to determine if the use of an educational intervention program, including a bladder diary and verbal reminders provided by staff, can decrease the number of incontinence episodes (wet undergarments) in individuals with SB at summer camp. The PICO question guiding this project was: In individuals with SB attending summer camp, does education and a two-pronged reminder system decrease the number of wet undergarments during a one-week camp? This project exemplifies Doctor of Nursing Practice (DNP) essential VII entitled “Clinical Prevention and Population Health for Improving the Nation’s Health.” This essential is met by the focus on prevention of pressure ulcers to improve health.

Review of Literature

Education and plans for pressure ulcer prevention self-care in individuals with SB is notably lacking in clinical practice and recommendations. More than 85% of pressure ulcers in individuals with SB develop in the community and tend to be related to a lack of preventative interventions and education (Ottolini et al., 2013). Kim et al. (2015) reported a 22% increase in incidence of pressure ulcers related to incontinent individuals when compared to continent individuals. Urinary incontinence affects forty-eight to seventy-six percent of individuals with Spina Bifida (Fischer, Church, Lyons, & McPherson, 2015). Cai et al. (2016) found increased pressure ulcer development in individuals with SB including low back (37%), hips (29%), and buttocks (41%) compared to other locations. The development of a single pressure ulcer increases the risk for development of additional pressure ulcers by 50% (Ottolini et al., 2013).

Mukherjee and Pasulka (2017) reported 34% of hospitalized individuals with SB were admitted with preventable complications, including pressure ulcers and a staggering 35% of them died as a result of complications from pressure ulcers while in the hospital.

Reduction of urinary incontinence in individuals with SB was addressed in this project through an intervention for campers and camp staff, that included education, implementation of a bladder diary and scheduled reminders by staff. Self-management skills play a key role in determining health outcomes and independence among individuals with SB (Yu, Parmanto, Dicianno, & Pramana, 2015). A bladder diary serves as an individual reminder of when they last performed a self-catheterization and the time of the next scheduled catheterization. Like reminders for blood glucose control, bladder diaries can enhance an individual's awareness of urinary patterns and incontinence episodes (Locher, Goode, Roth, Worrell, and Burigo, 2001). When recording a bladder diary, Locher et al. (2001) determined a consistency interval was reached at day five in individuals with urge incontinence meaning individuals who used the diary had fewer episodes of incontinence and more consistent bladder care at day five when compared to day one. Lifestyle modification, including timed catheterization, is the most effective first line prevention of incontinence (Ginsberg, Schneider, & Watanabe, 2015).

Conceptual Framework

Orem's Self-Care Deficit Theory was selected to guide this model. Dorothea Orem first published this theory in 1959, combining two of her other theories including Self-Care and Theory of Nursing. The concepts of this theory include self-care, self-care agency, therapeutic self-care, self-care deficit, nursing agency, and nursing system (Walton, 1985). Self-care is the initiation and performance of activities to maintain health and well-being. Self-care agency is the ability to perform self-care. Therapeutic self-care demand is the intervention to meet self-care

needs of the patient. Self-care deficit identifies the gap between demand and the ability to perform self-care activities. Nursing agency is the nurse's ability to meet the needs of the patient. The nursing system is the holistic scope of nursing care including responsibilities, roles, relationships, and actions (Orem, 2006).

Orem's Self-Care Deficit Theory helps to lay the foundation for this project by focusing on what a patient can do for themselves, assessing existing gaps in helping patients accomplish goals, the nurse's role in filling gaps in research, and leveraging nursing care to reduce the number of pressure ulcers with the reduction of episodes of incontinence. In the camp setting, individual campers are either able to perform catheterization independently, inform staff it is time for their catheterization, or assigned volunteers will notify staff for individuals unable to communicate. The identified gap in care is that campers are often excited about activities and forget to complete catheterizations on schedule. CTLB focuses on increasing independence and provides a unique opportunity to help campers increase compliance with catheterization and understand their role in pressure ulcer prevention. Therefore, the intervention for this project is designed to help remind campers when it is time to self-catheterize without diminishing independence and providing tools to use when they return home.

Specific Aims

Specific Aim #1: To decrease incontinence/overflow episodes in individuals with SB by:

- a. Use of a bladder diary to accomplish a reduction in urinary incontinence/overflow episodes (wet undergarments) as evidenced by a reduction in the number of incontinence episodes by two episodes documented on the Bladder Diary tool (National Association for Continence (NAFC) (2018) from day two to day five.

- b. Use of scheduled verbal reminders provided by staff members every four to six hours as evidenced by documentation of increased reminders by two reminders in the daily log kept by staff members from day two to day five.

Specific Aim #2: To increase knowledge of camp staff and campers related to the importance of preventing urinary incontinence/overflow episodes in individuals with SB by:

- a. improved attitude of pressure ulcer prevention by staff and campers as evidence by an 15% increased post- intervention score Pressure Ulcer Attitude Survey (PUAS) (Moore & Price, 2004),
- b. increased pressure ulcer prevention knowledge by staff and camper as evidenced by an increase on Pressure Ulcer Knowledge Assessment Tool (PUKAT) 2.0 (Manderlier et al., 2017) post- intervention.

Methods

Project Design

This is a QI project using a quasi-experimental design, pre-, post-intervention evaluation design.

Protection of Human Subjects and Confidentiality

This project is a QI project focused on prevention of pressure ulcers in individuals with SB attending CTLB camp. This was completed through process change in the CTLB camp setting, utilizing a bladder diary and an associated educational session to increase awareness and knowledge regarding pressure ulcers along with use of reminders both visually and verbally to perform scheduled catheterization and decrease overflow incontinence. A Determination of Non-Human Subjects was obtained from the Texas A&M University Corpus Christi Institutional Review Board (IRB) (provided in Appendix A). Protected Health Information (PHI) data was not

collected. No IRB approval was required to conduct this project at CTLB camp. The approval from the camp director and organization president to conduct this project are provided in Appendix B & C.

Participants

The target participation goal was to have 45 camper participants and 12 staff participants. The camp accepted 45 campers during this session. The camp included individuals ages 6 years and up and was inclusive of all gender identification and ethnicities. All campers and staff attending camp and meeting criteria were included through convenience sampling. This information was collected and recorded with the results. Participants were informed of the project through a recruitment letter when they applied to attend camp during the registration period from February to May 2019, (See recruitment letter in Appendix D). Inclusion criteria for the project included: 1) diagnosis for individuals of SB; 2) attendance of CTLB summer camp during the week of June 30th to July 5th; and 3) ability to perform intermittent self-catheterization or ability to notify staff when catheterization is needed, or ability to designate an assisted volunteer to notify staff when it is time for the catheterization. Inclusion criteria for staff included: 1) individuals who attended CTLB camp during the week of June 30th to July 5th; 2) current position of CTLB staff member; 3) consent to participation in the project.

Setting

CTLB is held at the Camp For All (CFA) facility in Burton, Texas. CFA is a residential accessible camp facility focused on individuals with a variety of illnesses and special needs. CTLB sessions include approximately 50 campers, 35 volunteers, and 15 staff members. Campers range from age 5 to 60 years of age and include all ethnicities and genders. A letter of

support was received from the President of the Spina Bifida Houston Gulf Coast Board, who sponsors the camp, and the Camp Director who oversees the camp (see Appendix E & F).

Intervention

The interventions selected for this project included using a bladder diary and an educational session focused on prevention of pressure ulcers in individuals with SB. The educational session was a 20-minute presentation led by the Project Director (PD) focusing on causes of pressure ulcers, prevention interventions, and altering medical staff regarding potential skin concerns. The session was provided to staff and campers planning to attend summer camp from June 30th to July 5th. The educational session was conducted for staff on May 18, 2019. The educational session for campers was conducted on June 15, 2018. The staff members and campers completed a pre-/post-test focused on the content in the educational session. The PUKAT 2.0 was used prior to the educational sessions and following completion of implementation of the bladder diary.

The bladder diary was selected to be completed in paper and pencil format due to poor phone signal and the camps strict policy of no phone use while at camp. The bladder diary included documentation of catheterization on a 24-hour schedule. The diary included time of day, volume voided, leakage, and activity at time of leakage. The bladder diary was kept by campers or the volunteer assigned to the camper and were always kept with the campers. Bladder diaries provided visual reminders of the last catheterization and when the next was indicated (Locher et al., 2001). The diary was reviewed by the PD for a one-week intervention, which has been determined to be a sufficient timeframe for effective utilization and behavior change for individuals with bladder incontinence (Locher et al., 2015). Research has demonstrated prevention of a pressure ulcer is more effective than treating an ulcer after its development

(Chou et al., 2013). The project team was trained in utilization of the bladder diary, documentation of verbal reminders, and pressure ulcer prevention. The educational session and bladder diary were utilized to improve catheterization schedules and reduce the number of urinary incontinence episodes.

Data Collection

Data collection began May 19th when the first education session was provided to the staff, who were asked to complete the PUKAT 2.0 and attitude assessment prior to the educational presentation. On June 16th, campers completed the educational session during camp orientation. The educational sessions were delivered by the PD and an educational handout with similar information was sent home with participants (See Appendix G). On June 30th (day one), when campers arrived at camp, they were given the bladder diary for the week and staff were given a schedule, including the times each camper is to be reminded to perform their catheterization, to document verbal reminders. June 30th -July 5th (days 1-6), campers were asked to complete the bladder diaries and staff were asked to provide verbal reminders to the camper about completing their bladder programs. Reminders were given by camp staff members after each activity. These tools were collected on July 5th. After implementation of the bladder diary from June 30 to July 5th, all participants completed the post-intervention PUKAT 2.0 and the PUAS. The timeline figure and table are provided in Appendix E.

The project team included the Project Director (PD), camp director, and the medical staff (Registered Nurses [RNs] and Nurse Practitioners [NPs]). The PD provided the educational session and collected and analyzed data from the project. The camp director assisted with the educational session planning and implementation at the camp and served as a content expert. The nursing staff spot-checked the bladder diaries and provided catheterization for campers needing

assistance. Training for the medical staff was provided by the PD including implementation of the bladder diary and expected role in the project while at camp.

Measurement tools. Outcomes for this project included diary entries of pre- and post-intervention number of wet undergarments, measurement of both camper and staff attitude related to prevention of pressure ulcers, and measurement of staff and camper knowledge of pressure ulcer prevention. The number of wet undergarments was measured using a bladder diary adapted from National Association for Continence (NAFC) (NAFC, 2018) and included data including time and date voided, measured amount voided, wet/dry undergarment, activity during leakage, and nursing assistance provided, if any. The use of a bladder diary is evidence-based and has been validated using a test-retest model with results reported using the Spearman correlation (0.49-0.88), which found the diary valid and reliable for producing change (Bright, Cotterill, Drake & Abrams, 2014). The attitude of campers and staff related to prevention of pressure ulcer was evaluated using a Pressure Ulcer Attitude Survey (PUAS) from Moore and Price (2004). Reliability for option-based questionnaires is dependent on the honesty of responses and provides information about areas for educational focus.

The PUKAT 2.0, adopted from Ghent University in Belgium (Manderlier et al., 2017), is designed to evaluate knowledge of the staff before and after the project intervention focused on pressure ulcer prevention. The PUKAT 2.0 was tested for reliability using the test-retest procedure with an overall intraclass Correlation Coefficient of 0.69 (Manderlier et al., 2017) . The tool also has a reliability correlation of 0.7-0.8. The results collected from the number of wet undergarments, attitudes of the campers and staff, and the knowledge of staff members were analyzed to determine if the intervention was effective and identify trends for future interventions.

Data management. Information from the study was collected and kept by the PD in a locked box during the intervention and analysis portions of the study. Participants were given the option to keep their bladder diaries once the information was inputted. Diaries not returned to participants were turned over to the organization for storage in compliance with organization regulations. Participant names remained on the bladder diaries; however, no identifiable participant information was utilized in the analysis or reporting portions of the project. At completion of the analysis, bladder diaries were returned to the camp director, who secured them with the remainder of the documents from the camp for that year. Documents are kept in a secure location for a length of ten years in accordance with Spina Bifida Houston Gulf Coast organizational policy.

Data Analysis

Bladder diaries were collected by the PD daily and reviewed for episodes of incontinence and interval consistency of catheterization. The number of overflow episodes were recorded on a run chart from day one to day five. The run chart allows for a greater detection in decrease number of incontinence episodes (wet undergarments). A downward trend was seen from day one to day five. The interval of catheterization was also reviewed for consistency and documented according to the number of times the individual remained on schedule. This was evaluated using a run chart to determine any change frequency from day one to day five. The pre-tests were collected prior to the educational session by medical staff and reviewed by the PD. The post-test were collected following the educational session by the PD. Results of the post-test were compared to the pre-test using a *t*-test. The correlation of the results was then reported. The PUAS survey was given with the pretest and again after completion of the bladder diary at camp.

The results were then compared using a *t*-test to determine the statistical significance related to the awareness of pressure ulcer prevention.

Results

Outcomes

The project began with creation of the educational session designed by the project team. Sixty-one participants participated in the project (n=61). Participants ranged from ages 5 to 58 years old. There were 35 females and 26 males. There were 11 individuals under the age of 18, 48 from the age of 19-55, and two over the age of 55. There were 37 Caucasians, 12 Hispanics, 11 African Americans, and one listed as other (See Appendix H, Table 1). Following implementation of the bladder diary at camp (June 30th to July 5th), the posttest was administered. Thirty-five of the sixty-one individuals had an increase from pre to PUKAT 2.0 post-test scores by 10% or greater ($t=4.581$) (See Appendix H, Table 2). Thirteen individuals had a decrease in the post-test score. Fourteen individuals' scores did not change from the pre- to the post-test.

Participants were given a PUAS survey upon arrival to the educational session and at the completion of the one-week summer camp the results were collected and reviewed by the project director. The PUAS found a two percent increase in attitude scores from pre- intervention to post-intervention ($t=-15.94$) (See Appendix H, Table 3). Forty-six of the participants diagnosed with Spina Bifida completed the bladder diary (n=46). Eight individuals were excluded: one with an indwelling catheter bladder management, one with a urostomy system, one with a condom catheter, and five who did not perform catheterizations on a schedule.

Individuals with Spina Bifida were given a bladder diary to track their bladder management when they arrived at camp on June 30th. Diaries were collected by the PD daily. Fifteen of the participants were camp staff members without Spina Bifida and did not complete a

personal bladder diary. The rate of urinary incontinence episodes from day one to day five decreased by an average of 10 (20%) episodes per day ($P= 0.04$). Episodes of urinary incontinence decreased by 81% (37 episodes on day two and seven on day five) (See Appendix H, Table 4).

The bladder diary and associated educational session increased awareness and decreased incidence of overflow incontinence in participating campers. Information from this study will help decrease the risk of pressure ulcers in individuals with SB. Campers were also observed by medical and camp staff checking the diary to determine when they needed to perform their next catheterization. The medical staff found the bladder diary can also be used as a tool to determine hydration status related to urine output totals. Additional attention will be needed to determine the long-term effects of prevention of overflow incontinence.

Discussion

Summary and Relation to Other Evidence

The bladder diary and educational session provided camp staff members and camper participants with increased understanding of pressure ulcer prevention. Although addition of the bladder diary altered the routine for the individuals with SB, overall response to the diary has been positive. The diary will continue to be used and implemented at camp in years to come. The organization will continue to support the use of the diary and encourage individuals to use the diary at home. The response by the individuals with SB showed enthusiasm about the change and excitement to participate in future projects focused on health improvement. The camp staff and medical staff also had favorable responses to the interventions, as they saw decreased workload related to overflow incontinence and increased morale due to enhanced independence. Campers and staff members voice appreciation for the intervention and identified additional benefits

including increased time at activities, less trips to the cabins to change wet clothing, and increased attentiveness to the bladder diary and catheterization schedule.

Self-management has been identified as one of the gold standards in research for pressure ulcer prevention (Ginsberg, Schneider, & Watanabe, 2015). Research has recently shifted from management to prevention, resulting in most research focusing on contributing factors for pressure ulcers rather than prevention (Mukherjee & Pasulka, 2017). Though subjects of other studies have not been individuals diagnosed with SB, implementation of a bladder diary and associated educational program have been found to decrease overflow episodes and decrease the number of pressure ulcers in similar populations individuals with spina cord injuries, stroke patients, or other individuals living with neurogenic bladders (Ginsberg, Schneider, &Watanabe, 2015).

Limitations

The project included participants centrally located at the camp during the intervention and placed in contact with the project team at all times during the study. While the participants functioned independently of the project team, considerations would need to be made to ensure participants have unrestricted access (via email, phone, or text) to the medical team in the future to assist with medical needs when requested. Additional considerations should be made to tailor further projects separating individuals who are completely independent from those requiring assistance. Once returning home from camp individuals may experience potential challenges regarding sustaining behavior change including lack of needed supplies to perform catheterization more frequently and a form of the diary that can be easily reproduced for each day. This could be mitigated by creating an application for a smart phone that can be used as a bladder diary and for audible reminders when catheterizations are due. Finally, to improve

longevity of bladder diary utilization an electronic version with a smart phone application could also prove beneficial. This would replace the need for a verbal reminder and allow access anytime or anywhere. Additional projects will need to be conducted to determine longevity of the intervention and application in a less controlled outpatient environment.

Interpretation

The knowledge assessment proved to be successful with an increase in the mean score of 11 points from pre- to post-intervention scores. The attitude survey did not yield statistical significance but did provide clinical significance. When reviewing the results of the surveys it appeared some of the participants just marked down the middle or placed random marks instead of reading and answering the questions honestly. While the bladder diary did yield positive results long-term implementation of a diary can prove to be difficult to maintain in the current paper and pencil format. Additional attention should also be given to the bladder diary to identify a method to make it accessible via smartphone application. The reminders could also be set up on the smartphone devices. Moving the diary to a smartphone application from a traditional paper and pencil method could increase attentiveness of the younger generations. This could be accomplished with the addition of an information technology expert to the project team. The cost of the project was relatively low, and benefits can be significant. The overall cost of the project was fifty-four dollar due to the camp and medical staff donating their time during the project(See Appendix I). The cost to treat one pressure ulcer can be up to \$151,700 yielding the QI project both clinically significant and cost effective. Additional cost may result from the addition of a smart phone application, though the cost would still remain small compared to the thousands of dollars required for the effective management of one wound.

Conclusion

Implementation of a bladder diary and educational session yielded positive results and increased awareness among individuals with SB and all staff members. The education session and diary have been adopted by the organization and will be integrated into camp procedures moving forward. The diary will remain in paper and pencil form at camp due to poor cellular signal and camp policy that phones are not used during activities. The cost for implementation was absorbed by the camp as part of their initiatives to improve the independence and health of the campers. Additional cost may be accrued when a decision is made to move the paper and pencil method to a smartphone application. This decision has been placed on hold regarding the camp and organization due to other concerns related to phone signal and the distractions of smartphones during camp activities. This project can be expanded to assist other special populations as well as caregivers. This study demonstrated a simple but impactful intervention that can change the lives of individuals that are at risk of pressure ulcer development.

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APPENDIX A: IRB Approval Letter



OFFICE OF RESEARCH COMPLIANCE
Division of Research, Commercialization and Outreach
6300 OCEAN DRIVE, UNIT 5844
CORPUS CHRISTI, TEXAS 78412
O 361.825.2497

Human Subjects Protection Program Institutional Review Board

DATE: January 2, 2019
TO: Jessica Peck, Nursing and Health Sciences
CC: Donna Schumann, Student
FROM: Office of Research Compliance
SUBJECT: Not Human Subjects Determination

Activities meeting the DHHS definition of research or the FDA definition of clinical investigation and involves one or more human subjects are subject to IRB review and approval.

On January 2, 2019, the Texas A&M University-Corpus Christi Institutional Review Board reviewed the following submission:

Type of Review:	Not Human Subjects Determination
Title:	Reduce Overflow Incontinence to Help Prevent Pressure Ulcers in Individuals with Spina Bifida
Project Lead:	Jessica Peck
IRB ID:	NHS 50-18
Funding Source:	None
Documents Reviewed:	D. Schumann 600.02 Form, Not Human Subjects Research Request (2) D. Schumann 600.02 Template, Quality Improvement Project (3) CAMP THAT LOVE BUILT BLADDER DIARY Pressure Ulcer Attitude Survey PUKAT 2.0 Letters of support (jodia and KIM)

Texas A&M University-Corpus Christi Office of Research Compliance determined that the proposed activity does not meet the DHHS definition of research or the FDA definition of a clinical investigation.

Therefore, **this project does not require IRB approval.** You may proceed with this project.

This determination applies only to the activities described in the documents reviewed. **Any planned changes require submission to the IRB to ensure that the research continues to meet criteria for a non-human subject research determination.**

Please do not hesitate to contact me with any questions at irb@tamucc.edu or 361-825-2497.

Respectfully,

Rebecca Ballard, JD, MA, CIP
Digitally signed by Rebecca Ballard, JD, MA, CIP
Date: 2019.01.02 09:53:05 -06'00'

Rebecca Ballard, JD, MA, CIP
Director, Research Compliance
Division of Research, Commercialization and Outreach

APPENDIX B: Camp Director Letter of Support



20 October 2018

Dr. Yolanda Keys
Associate Dean for Academic Programs
College of Nursing and Health Sciences
Texas A&M University – Corpus Christi
6300 Ocean Drive
Corpus Christi, TX, 78412

Dear Dr. Keys,

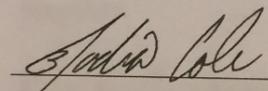
The purpose of this letter is to provide Donna Schumann, a Doctor of Nursing Practice student at Texas A&M University College of Nursing and Health Sciences, support in conducting a quality improvement project at Camp That Love Built sponsored by Spina Bifida Houston Gulf Coast. The project Reduce Overflow Incontinence to Help Prevent Pressure Ulcers in Individuals with Spina Bifida, entails an educational session for campers and staff focused on pressure ulcer prevention and the implementation of a bladder diary utilized by campers while at camp.

The purpose of this project is to decrease episodes of overflow incontinence, increase awareness and understanding of pressure ulcer prevention. Camp That Love Built was selected for this project because there is currently no process in place focused on pressure ulcer prevention and prevention of overflow incontinence. Donna Schumann is not employed, but is a volunteer at this institution, and has an interest in improving care at this facility.

I, Jodia Cole, Camp Director, at Camp That Love Built, do hereby fully support Donna Schumann in the conduct of this quality improvement project, Reduce Overflow Incontinence to Help Prevent Pressure Ulcers in Individuals with Spina Bifida at Camp That Love Built.

If you have any questions or concerns, please feel free to email me at CTLBdirector@yahoo.com, and I will be happy to help wherever I can.

With My Most Sincere Gratitude,



Jodia Cole
Camp That Love Built
Camp Director

APPENDIX C: SBHGC Organization Letter of Support



20 October 2018

Dr. Yolanda Keys
Associate Dean for Academic Programs
College of Nursing and Health Sciences
Texas A&M University – Corpus Christi
6300 Ocean Drive
Corpus Christi, TX, 78412

Dear Dr. Keys,

The purpose of this letter is to provide Donna Schumann, a Doctor of Nursing Practice student at Texas A&M University College of Nursing and Health Sciences, support in conducting a quality improvement project at Camp That Love Built sponsored by Spina Bifida Houston Gulf Coast. The project Reduce Overflow Incontinence to Help Prevent Pressure Ulcers in Individuals with Spina Bifida, entails an educational session for campers and staff focused on pressure ulcer prevention and the implementation of a bladder diary utilized by campers while at camp.

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I, Kimberly McCuiston, President, Board of Directors, at Spina Bifida Houston Gulf Coast, do hereby fully support Donna Schumann in the conduct of this quality improvement project, Reduce Overflow Incontinence to Help Prevent Pressure Ulcers in Individuals with Spina Bifida at Camp That Love Built.

If you have any questions or concerns, please feel free to email me at texmacs7@yahoo.com, and I will be happy to help wherever I can.

Sincerely,

Kimberly McCuiston
Spina Bifida Houston Gulf Coast
President, Board of Directors

APPENDIX D: Letter Sent to Potential Participants

Hello Everyone!

As we prepare for Camp That Love Built 2019, I would like to take a moment to discuss a unique opportunity our campers and their family members will have this year. We are focusing on the health and wellness of our campers related to prevention of pressure ulcers. We are conducting a quality improvement project with the goal of this project is to improve the health of our campers by reducing the risk associated with pressure ulcer development. As many of you know or have experienced, pressure ulcers are painful, financially costly and harmful to our campers in more ways than one. Through a review of literature, it has been found that altering daily routines and processes are the primary interventions to reduce the risk of pressure ulcers to include ensuring bladder care is performed on schedule to prevent overflow/incontinence episodes.

This project will provide education to the campers and staff members, a bladder diary to act as a visual reminder, and verbal reminders from staff to ensure campers perform their bladder care on schedule. All participants will be asked to fill out a survey on their knowledge and attitude toward pressure ulcers, at the beginning and end of camp. We will use the bladder diary to monitor the number of wet undergarments per day. We hope to improve our campers' awareness, understanding, behaviors regarding pressure ulcer prevention. Reduced episodes of wet undergarments will decrease the number of times the skin is exposed to an irritant such as urine. I look forward to working with all the campers this year. If you have questions, please contact me at the email listed below.

Sincerely,

Donna Schumann MSN, RN, FNP-C
Camp That Love Built Medical Director
ctlbmedstaff@yahoo.com

APPENDIX E: Timeline for Project Focused on Reduction of Urinary Incontinence Episodes

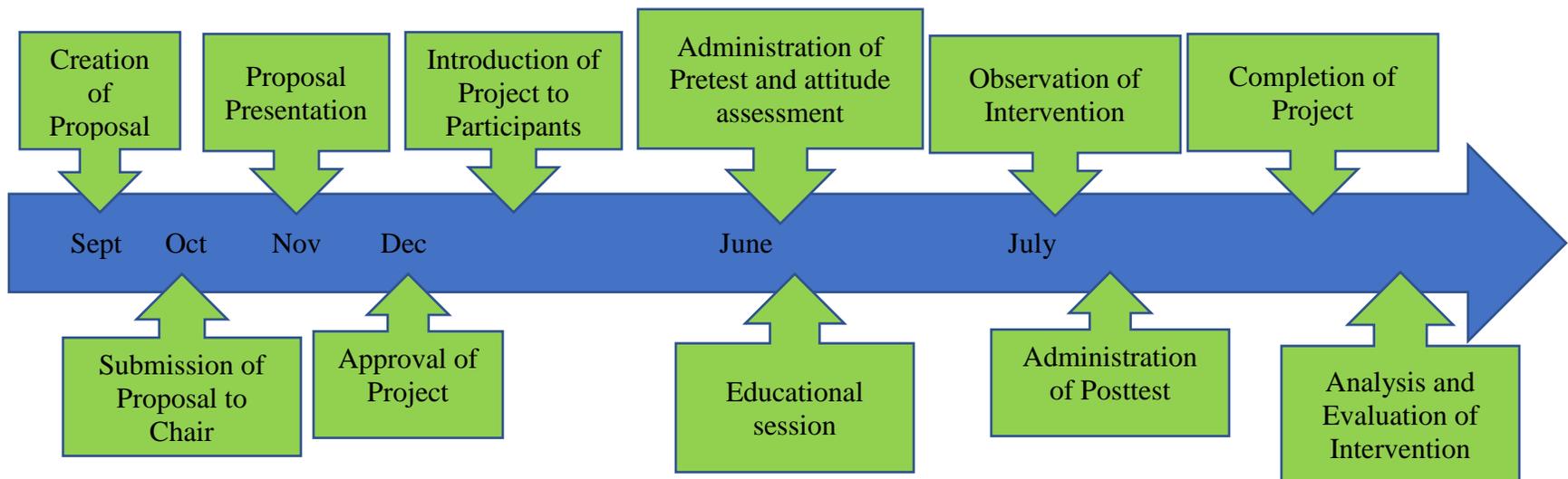
Table E1

Timeline for Project Focused on Reduction of Urinary Incontinence Episodes

Task	August 18	September 18	October 18	November 18	December 18	January 18	February 18	March 18	April 18	May 18	June 18	July 18
Selection of Project Topic												
Selection of Team Members												
Selection of Intervention												
Selection of Evaluation												
Creation of Proposal												
Submission of proposal												
Approval of Proposal												
Obtain Letter of Support												
HEOC Letter												
IRB Approval												
Make copies of Pre/Posttest												

Prepare introduction presentation												
Introduction to participants												
Administration of Pretest												
Educational session												
Administer attitude assessment												
Observation period												
Administration of posttest												

Figure E1. Timeline for Project Focused on Reduction of Urinary Incontinence Episodes



APPENDIX F: Risk Assessment for Project Focused on Reduction of Urinary Incontinence

Episodes

Table F1

Risk Assessment for Project Focused on Reduction of Urinary Incontinence Episodes

Risk	Impact	Countermeasure	Facilitators	Barriers
1. Lack of participant engagement because of perception that the project will interfere with fun camp activities.	Decreased reliability of the study due to a small sample size.	Ensure the participation will enhance the camp experience and not interfere with the fun.	Work with camp administrative staff to ensure the process is seamless and runs smooth.	Lack of camp administrative support for the project.
2. Participant perception of knowledge provided is knowledge previously acquired with subsequent lack of engagement or recognition of the intervention benefit.	Decreased accuracy due to poor participation.	Updated and new information is provided in an engaging and relevant way with emphasis on new knowledge attainment.	Work with the camp administrative staff to ensure the importance and support for the project is clear to participants.	Identifying information that appeals to the staff and campers.
3. Short duration of the study intervention.	Decreased reliability and validity of the study.	Ensure that the process is well thought out and all participants are ready to participate prior to the start of the project.	Work with camp administrative staff and project team to ensure all participant and materials are ready before the start of the project.	Not having everyone onboard and ready at the start of the project.

APPENDIX G: Flyer Given to Participants with Information Related to Pressure Ulcer Prevention

Key Points

1. Keep Moving!
2. Keep on schedule with bowel and bladder program.
3. Maintain a healthy weight.
4. Perform skin care checks often.
5. Report concerns early.

**Everyone
is
Responsible**

*Preventing Pressure Ulcers in
Individuals with Spina Bifida*



*Individuals with Spina Bifida
are at an increased risk for
pressure ulcer development. As
a team we can help prevent
pressure ulcer by decreasing the
risk.*

What is Spina Bifida?



Spina Bifida is congenital birth defect resulting in neurovascular, cognitive, and decreased or absent motor function. One of the greatest challenges faced by individuals with Spina Bifida from all ages is pressure ulcers. A survey conducted in 2017 found that an average of 30-50% individuals with SB will develop a pressure ulcer at some point in their lives. The increased life expectancy of individuals with Spina Bifida has led to a need for change in focus from treatment to prevention interventions for these individuals. The Agency for Healthcare Research and Quality identified the cost of one pressure ulcer is between \$20,900 and \$151,700. Given the overall rate of development of pressure ulcers, the annual cost is \$3.5 billion for a preventable problem.

What is a pressure ulcer?

A pressure ulcer is any area of localized skin breakdown in an area of greater bony prominence including the buttocks, heels, and hips.

Pressure ulcers develop as a result of pressure, skin irritants, decreased activity and friction.

Other factors that play a role in pressure ulcer development include wet undergarments, decreased sensation, increased body temperature, individuals who are overweight or underweight.

How do we Prevent Pressure Ulcers?

Pressure ulcers can be prevented through lifestyle

modifications. These modifications include:

- Reduction in pressure
- Reduction in exposure to skin irritants
- Reduction in friction
- Increased activity
- Maintaining a healthy body weight.



What is your role?

Pressure ulcer prevention is a group effort. The individuals with Spina Bifida and the nurses/caregivers are not the only ones responsible for the prevention of pressure ulcers. Every person either directly or indirectly plays a role in the prevention of pressure ulcers. Individuals need to perform their bowel and bladder care on schedule, skin checks should be performed frequently, and pressure should be shifted at least every 30 minutes to prevent skin breakdown. Family, friends, camp staff, and medical staff can help by providing the individual with reminders and assistance with completion of tasks when requested.

APPENDIX H: Project Results including Demographics, PUKAT 2.0, PUAS, and Bladder Diary

Table H1
Demographics for Campers and Staff Participants

Demographic	Camp Staff (n=16)	Campers (n=45)
Gender		
Male	10	25
Female	6	20
Ethnicity		
Caucasian	11	26
Hispanic	2	10
African American	2	9
Other	1	0
Age		
Under age 18 Years	0	11
19-55 Years	15	33
56+ Years	1	1

Table H2
Pressure Ulcer Knowledge Assessment Test (PUKAT 2.0) Results for Staff and Campers

PUKAT 2.0	Mean	N	Std. Deviation
Pretest	41.15	61	17.710
Posttest	52.62	61	19.740

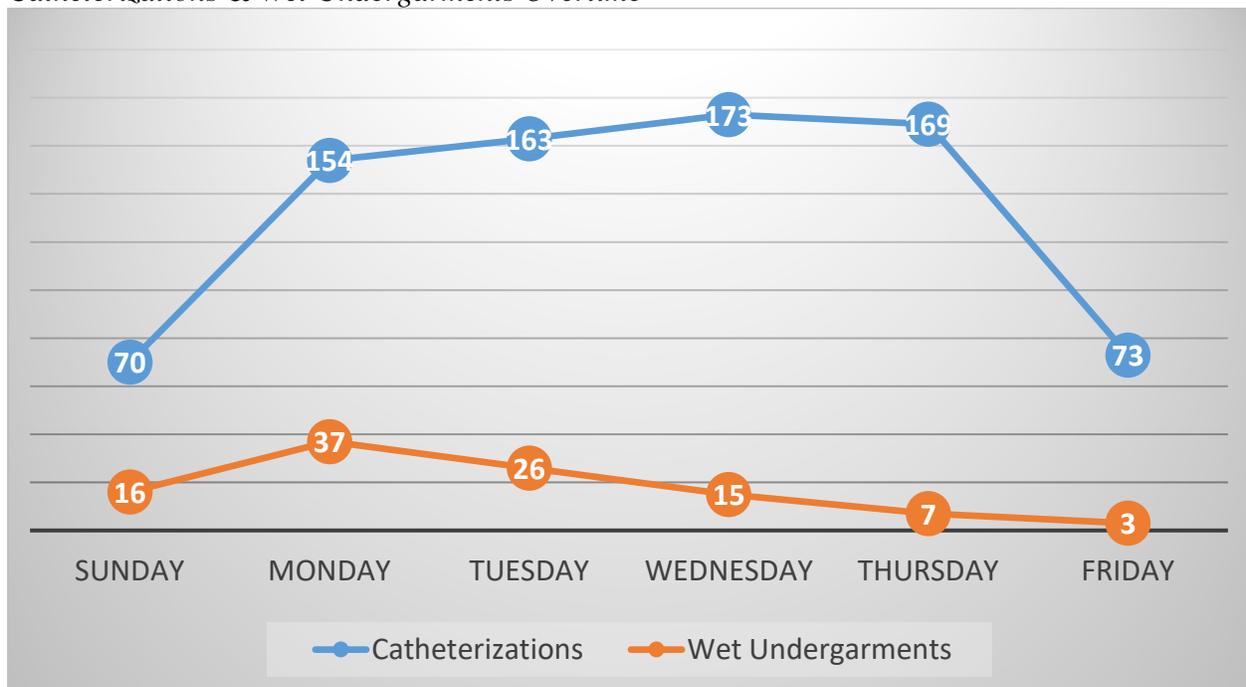
Measurement	Value
Mean	11.475
<i>t</i>	4.581
<i>df</i>	60
Sig (2-tailed)	.000

Table H3
Pressure Ulcer Attitude Survey (PUAS) Results for Staff and Campers

PUAS	Mean	N	Std. Deviation
Preattitude	38.25	61	5.421
Postattitude	39.03	61	5.879

Measurement	Value
Mean	.787
<i>t</i>	1.150
<i>df</i>	60
Sig (2-tailed)	.255

Table H4
Catheterizations & Wet Undergarments Overtime



APPENDIX I: Project Budget

Table I

Budget for Project Focused on Reduction of Urinary Incontinence Episodes

Cost Category	Budget	Actual	Difference	Description/Comment
PROJECT EXPENSES				
Copies (300 sheets)	\$20.00		\$42.00	
Folders (70 folders)	\$20.00		\$7.00	
Writing utensils (70)	\$10.00		\$5.00	
Medical Staff (120 hrs /member)	\$0		\$0	Hours are donated. 5 members
Camp Staff (120 hrs /member)	\$0		\$0	Hours are donated. 9 members
Administrative Staff (120 hrs /member)	\$0		\$0	Hours are donated. 2 members
Total Project Expenses	\$50.00		\$54.00	
PROJECT REVENUE				
Total Project Revenue				
PROJECT BENEFIT/LOSS				
Total Revenue				
Less Expenses	-\$54.00			
TOTAL PROJECT BENEFIT/LOSS				

APPENDIX J: Evaluation Tool

