Assessing Transition Readiness in Pediatric Neurosurgery Patients

A Quality Improvement Project

Wendy Domreis, MSN, RN, CPNP-PC

Oregon Health & Science University School of Nursing

Submitted to Sharon Norman, DNP, RN, CPNP-PC, CNS, CCRN-K

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Abstract

The Hydrocephalus Association recommends pediatric neurosurgery providers use the Got Transition "Six Core Elements of Health Care Transition"(https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) to improve the process of transitioning pediatric patients with hydrocephalus to an adult model of care.

At the hydrocephalus clinic in an academic institution in the Pacific Northwest, caregivers and patients are informed along the healthcare continuum that patients are followed in the pediatric neurosurgery clinic until they are 18 years old, at which time they are expected to transition to adult neurosurgery care; however, readiness to transition care has not been formally assessed.

The aim of the quality improvement project was to formally assess transition readiness in 14-18-year-old patients seen during routine hydrocephalus clinic visits in January and February of 2023.

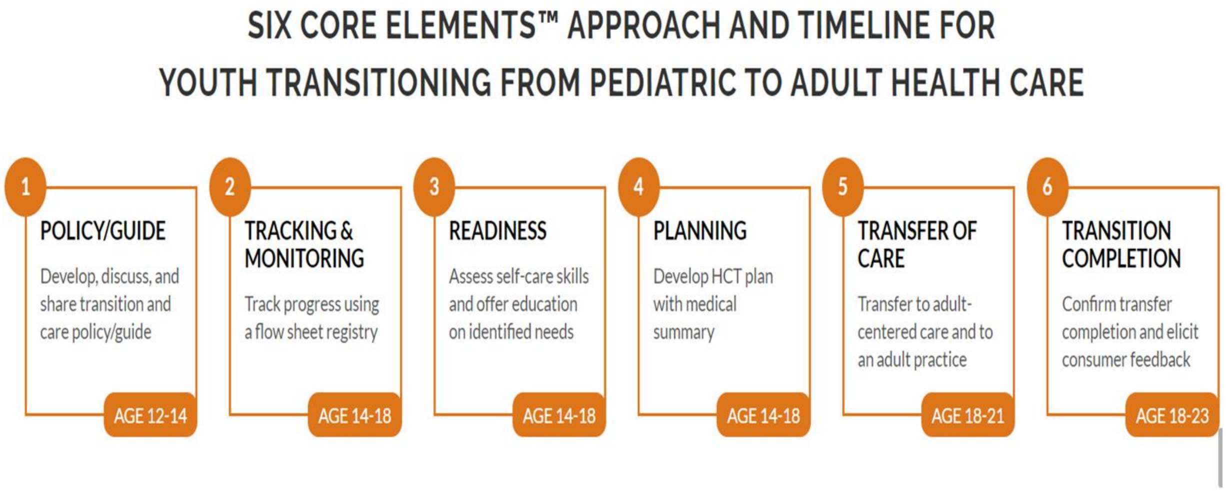
The Institute for Health Improvement (IHI) Model for Improvement (MFI) and the Plan-Do-Study-Act (PDSA) was used to guide this quality improvement project. The Got Transition "Six Core Elements of Health Care Transition" (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) readiness assessment survey tool was utilized. There was a wide range of pre and post-visit scores. All caregivers and 80% of patients' transition readiness scores improved after the clinic visit. Assessing transition readiness is an important step in the transition process and performing a readiness assessment survey pre and post-clinic visits can assist pediatric nurse practitioners in setting patients and caregivers up for a successful transition to adult neurosurgical care.

Problem Description

Hydrocephalus results from an abnormal cerebrospinal fluid (CSF) accumulation in the ventricles, increasing intracranial pressure which causes macrocephaly, cognitive impairment, and if left untreated, death (Gibbs, W.N., & Tanenbaum, L.M., 2018). The World Health Organization-affiliated International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) estimates that the incidence of congenital and acquired infant hydrocephalus may be between 80 and 125 cases/100,000 births annually depending on the world region (Tamber, M.S., 2021). Results from a systemic review and meta-analysis report by Dewan et. al. (2018) state the incidence in North America is around 68 per 100,000 births. It is one of the most common childhood brain disorders and while it can be treated it is not curable (Hochstetlar, A., 2022). Treatment involves a surgical procedure that diverts cerebrospinal fluid, either by performing an endoscopic third ventriculostomy (ETV) or implantation of a ventriculoperitoneal shunt (VPS). While these procedures are life-saving, there is a high failure rate and thus a need for continued surgical intervention and management of these patients by a neurosurgical team throughout a patient's lifespan (Hochstetler, A. et.al., 2022). Each year approximately 5000-6000 patients must transition from a pediatric model of neurosurgical care to an adult neurosurgery practice (Williams, M.A., et.al. 2018).

A pediatric hydrocephalus clinic in an academic center in the Pacific Northwest cares for patients until the age of 18, at which time they are expected to transition to an adult neurosurgical practice. According to the Got Transition "Six Core Elements of Health Care Transition", (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm)(see Figure 1) preparation should begin in early adolescence (12-14yo) starting with a discussion of the policy for transition and as an iterative process ensuring readiness for transition through continued anticipatory guidance at subsequent clinic visits with the goal of the patient successfully moving along the continuum of healthcare, being able to self-manage their illness and successfully access health services (Roque, B.G., et. al., 2020; Li, et. al., 2022). The transition policy is discussed with our patients and caregivers regularly; however, our team does not formally assess if patients and caregivers are ready for this transition.

Figure 1. Six Core Elements (https://www.gottransition.org/six-core-elements/)



Available Knowledge

Patients with hydrocephalus lead productive lives and survive well into adulthood (Isaacs, et al., 2018). According to Gmeiner (2017), while mortality is significant in the first year of life, it continues to be significant in adult years as death occurs even after age 20, reinforcing the need for continued routine follow-up after age 18. The American Academy of Pediatrics (APP) recommends that pediatric patients transition from pediatric to adult medical care between 18 and 22 years of age (White, P.H. et.al., 2018). In 2017, The Hydrocephalus Association (HA) held a transition of care summit and recommended pediatric neurosurgeons incorporate the Got Transition "Six Core Elements of Health Care Transition" (HCT) (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) to standardize the process of transitioning care of patients with hydrocephalus to adult medicine (Williams, M. A.,2018). The American Society of Pediatric Neurosurgeons (ASPN) supports using this HCT guidance noting that an unorganized transition of care can lead to poor health outcomes, increased healthcare utilization, lengthy hospital stays, increased morbidity, increased costs, and increased stress for patients and caregivers (Hong, et. al., 2021; Rocque, B.J., et.al 2020). Despite these recommendations, a structured approach to the transition of care for pediatric patients with hydrocephalus has yet to be established nationally. Transition practices are poor with more than 85% of practicing neurosurgeons scoring transition readiness as very low in their practice (Roque, et. al., 2020). According to data collected by the National Survey of Children's Health, only 15% of pediatric patients receive any formal preparation for the transition of care (White, et. al, 2018). The planning for health care transition for all youth, whether they have specialized care needs or not, should begin in early adolescents with the goal of improving the ability to manage their health needs on their own (Roque et.al., 2020; White et. al, 2018). The 2011 clinical report on healthcare transitions from The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) recommends using the Got Transition "Six Core Elements of Health Care Transitions" (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) to accomplish effective transition of care for youth (White, et. al., 2018). Got Transition (Six Core Elements of Health Care Transition, 2023) essentially provides a roadmap and tools for providers to help guide the transition to adult medical care. Transition programs exist for type 1 diabetes, cystic fibrosis, and rheumatic disease, yet a structured model for transitioning patients with hydrocephalus and ventriculoperitoneal shunts is lacking (Johnson, et.al., 2021). The lack of coordination in transition leads to a decrease in routine care appointments after age 21 for spina bifida patients with hydrocephalus (Domino, J.S., et. al., 2022). A consensus statement from the American Society of Pediatric Neurosurgeons (ASPN) was published after a survey of 178 North American pediatric neurosurgeons revealed that most neurosurgical practices have poorly structured methods of transitioning patients and families to adult neurosurgical care (Roque et.al., 2020). Patients with complex medical needs report feeling abandoned by their healthcare providers and the healthcare system (Berkowtiz & Lang, 2020). Patients with hydrocephalus are often told that no routine follow-up is needed unless shunt failure is suspected, at which time they should just present to an emergency room (Williams, et. al., 2018). In the study by Hong et. al. (2021), it is reported that the overall incidence of shunt failure in adult patients with pediatric-onset hydrocephalus was 82.9%. Failure to assist patients/families in their transition of care results in poor health outcomes, increased hospital costs, inefficient use of emergency departments, and increased morbidity (Roque, et. al. 2020; Szalda, D., et.al., 2019).

Rationale

Our clinic policy is to care for pediatric hydrocephalus patients until they turn 18 years of age. Pediatric neurosurgical patients and their families often do not feel ready to transfer care to an adult neurosurgery care model, like other pediatric patients with chronic medical conditions, they often feel abandoned and their medical care is often disrupted during the transition process (Szalda, D., et. al, 2019).

Despite recommendations from the Hydrocephalus Association to utilize the Got Transition "Six Core Elements of Health Care Transition, (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) (Williams, et. al, 2018), there is no formal assessment of patient and caregiver transition readiness in our clinic.

The goal of a structured transition process is to improve the ability of youth to manage their health and utilize health services independently (Roque, et. al. 2020). Through a review of the literature, it was determined that the Got Transition "Six Core Elements of Health Care Transition" (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) could help guide advanced practice providers in establishing a formal transition of care program.

This quality improvement (QI) project was guided by the Institute for Health Improvement (IHI) Model for Improvement (MFI) which is used by healthcare quality improvement organizations as it provides a framework for change as the quality improvement projects progress. MFI was developed by the Associates in Process Improvement group and consists of two parts. The first part contains a group of questions: what are we trying to accomplish, how will we know that a change is an improvement, and what change can we make that will result in improvement? The second part of the MFI is the Plan, Do, Study, Act Cycle (PDSA) (Institute for Health Improvement, 2022). This model allowed for a rapid review of data providing the opportunity to make changes to improve the QI project based on findings after the first PDSA cycle. The creation of the cause and effect diagram (Appendix B) shows what contributing factors impact pediatric patients and their caregiver's lack of readiness to transition care to an adult model of healthcare. These factors include but are not limited to patients and caregivers not being aware of a transition policy, no formal assessment of readiness in the clinic, language barriers, anxiety and fear of establishing care with a new specialty provider, and frequent hospitalizations impacting patients' attendance in the hydrocephalus clinic where the clinic transition policy is often discussed.

Aim

According to the Got Transition "Six Core Elements of Health Care Transition", (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) framework, these six core elements should be used to help guide the transition of care to ultimately improve patient care (White, P. et. al., 2020). The aim of this quality improvement project was to assess readiness to transition health care from a pediatric to an adult model of care for 100% of patients scheduled in the hydrocephalus clinic during January and February 2023, who were between the ages of 14yo-18yo.

Context

This quality improvement project focused on a pediatric hydrocephalus clinic in an academic center in the Pacific Northwest. The clinic serves patients from Oregon, Alaska, Northern California, and Idaho. The pediatric neurosurgical practice consists of six pediatric neurosurgeons and three pediatric nurse practitioners. During the year 2021, the pediatric neurosurgery department performed 120 cerebrospinal fluid diversion procedures to treat hydrocephalus. The average number of patients who present to the pediatric hydrocephalus clinic is just under 200 per year. The current clinic policy is for patients to transition from the practice at age 18.

Interventions

For this QI project, the IHI model for improvement and PDSA cycles were implemented. The intervention was education based on results of a transition readiness assessment survey. The readiness assessment survey from the Got Transitions toolkit was used for the patient (see Appendix C) and caregiver The transitions toolkit survey has three sections: “Transition Importance & Confidence rating scale”, “My Health and My Health Care” which includes 20 questions, and “My Medicines” which has three questions. The surveys were distributed to patients and caregivers during the rooming process. The surveys were handed to the patients and caregivers by the medical assistant rooming the patients. In the first PDSA cycle, neither patient completed the rating scale portion, thus in PDSA cycle two this section was not included. The two patients seen during cycle one answered all 20 questions in the second section. Neither patient was on medication so the third section was not completed. The “My Health and Heath Care” questions were answered with either “no = 0”, “I want to learn = 1” or “yes = 2”. The total possible score was 40. The patient and caregiver were asked if there were any acute concerns that they wanted to discuss at the clinic visit (headache, vomiting). If there were no concerns the visit proceeded. After a neurological examination, attention was turned toward the readiness assessment surveys. The PNP reviewed the pre-clinic readiness assessment survey, and questions answered with “I want to learn” were used to guide the discussion and education provided during the clinic visit. The patients were given a health information summary (Appendix D), that included a QR CODE to download the Hydrocephalus Associations’ HydroAssist mobile application onto their smartphones. The mobile app was free to download. The PNP reviewed the most recent brain MRI with the patient and caregiver to ensure they understood the etiology of their hydrocephalus. The consent process was discussed and a release of medical information form was filled out. The referral process was reviewed and a referral was placed to an adult neurosurgery practice for patients who were 18.

The first two patients in PDSA cycle one, were given a satisfaction survey after the clinic visit (see Appendix E). This satisfaction questionnaire contained four questions and could be answered with a yes or no. This questionnaire was not scored and did not allow the PNP a way to measure improvement after the intervention therefore was determined ineffective and not included in PDSA cycle two. The second PDSA cycle included the next three patients scheduled in the clinic and followed the same format as PDSA cycle one, with the addition of the readiness assessment survey administered post-clinic as well.

This QI project did not impact clinic flow as the clinic template for these visits was lengthened in anticipation of the time needed to provide teaching, fill out forms, conduct a physical exam and complete the readiness assessment surveys.

Study of Interventions

The approach used to assess transition readiness was guided by the Got Transitions Six Core Elements of Health Care Transition (See Figure 1), focusing on step three: transition readiness. An initial transition readiness assessment was performed at the start of the clinic visit using the transition readiness assessment survey. During the first PDSA cycle, the tool was useful and allowed for the identification of skills needing review. Patients answered questions by checking a box for either “No”, “I want to learn”, or “Yes”. The patient questionnaire was used post-clinic in the first PDSA cycle but did not provide a way to compare scores to see if they had improved. Therefore, the second PDSA cycle incorporated the same readiness assessment survey after the clinic visit as well and provided a way to compare quantitative data.

Measures

The readiness assessment survey allowed a reliable comparison of scores from pre-clinic and post-clinic evaluation. A total score of 40 was the maximum. Scores were totaled before and after the clinic visit for patients and caregivers. Questions were asked about patients’ ability to explain their health needs, if they knew how to fill out medical forms, if they knew how to make an appointment, and if they knew how to seek care after hours to name a few. Balancing measures were taken into account during the first PDSA cycle by bringing all hydrocephalus patients to one provider’s clinic to decrease any impacts on the workload of other providers during the implementation of the QI project. After evaluating the data collected from the first PDSA cycle, the other PNP providers in the hydrocephalus clinic were included placing more emphasis on incorporating a team approach to the process of evaluating transition readiness. One patient was seen by another PNP provider but this data was not included since the patient did not fill out the survey completely.

Analysis

A total of eight patients were scheduled in this PNP's clinic that qualified for inclusion in the QI project. Of the eight patients only five were included in the QI project. One patient preferred to be seen by virtual visit. Two patients were experiencing acute symptoms of headache. There were 20 questions in the readiness assessment survey that were answered by all patients and caregivers with the potential to earn 40 points, total. Answering questions with a "No" earned zero points, answering with "I want to learn/they want to learn" earned one point, and answering with "Yes" earned two points. Data was collected on an Excel spreadsheet and scores were tallied. Questions answered with "I want to learn" were used to guide the intervention.

Ethical Considerations

The transition of care from a pediatric medical model to an adult medical model can be an emotional experience for patients and caregivers that have been cared for by the same providers for much of if not all of the patient's life. Care was taken to promote the protection of patient identity and healthcare information. Many of the patients in the practice are developmentally delayed and therefore the assessment of readiness will need to consider the caregiver's readiness primarily. The timing of the clinic visit was also considered prior to including the patient and caregiver assessment of readiness to transfer to adult care; for instance, if a patient had surgery within the past three months of the clinic visit they were not included in the QI project. There were two patients seen in the clinic with acute concerns therefore these patients and their caregivers were not included in the QI project. Although transition readiness was an outcome measured during this quality improvement process further iterations must include the actual transfer of care to an adult neurosurgery provider to promote continuity of care for these patients.

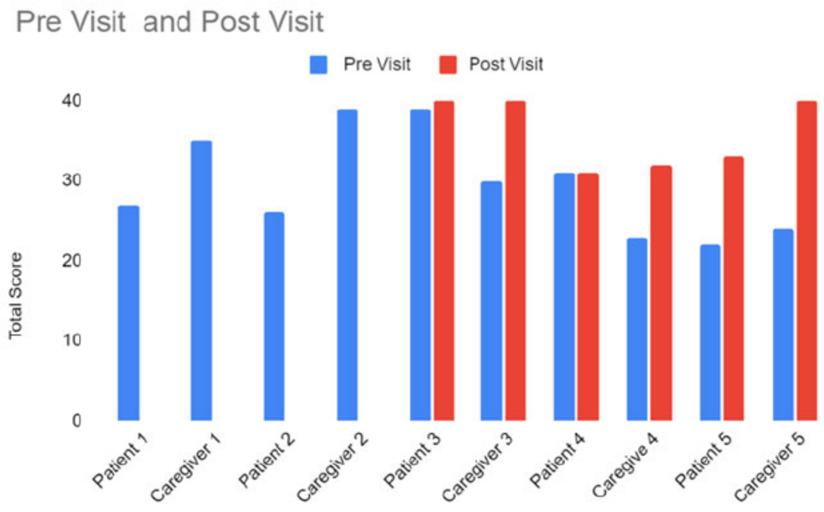
A request for determination was submitted to the IRB STUDY00025274 for determination of research in January 2023 and approved and determined to be a quality improvement project **(see Appendix H)**.

Results

For this QI project, a total of 62.5% of patients scheduled in hydrocephalus clinic were included. They ranged in age from 15-18 years old (See Table 1). Three were male and two were female. Two had acquired hydrocephalus secondary to an intraventricular hemorrhage of prematurity and three had congenital hydrocephalus related to aqueductal stenosis, myelomeningocele and cerebral cyst. All five patients had ventriculoperitoneal shunts. They each had at least one shunt revision, and one had up to 5 revisions total (See Table 1). All five patients presented to the clinic with their primary caregiver.

Patient's readiness assessment survey pre-clinic scores ranged from 22-39, and post-clinic scores ranged from 31-40. In comparison, the caregiver's pre-clinic scores ranged from 23-39, and their post-clinic scores ranged from 32-40. (See figure 2.)

Figure 2.



In PDSA cycle one there was no post clinic readiness assessment survey that was administered, rather the patients were given a satisfaction survey (see Appendix E) to which both patients answered yes to all the questions.

Table 1. Demographics

Patient	Age in years	Gender	Etiology	Shunt surgeries
1	15	Male	Acquired - IVH	4
2	17	Male	Congenital -AS	2
3	18	Female	Acquired -IVH	6
4	18	Female	Congenital-MM	2
5	18	Female	Congenital - Cyst	4

Trends noted on the patient’s readiness assessment survey were all five patients scored “2” for question 11, “I know at least one other person who will support me with my healthcare needs” and for question 15, “I have a way to get to my doctor's office”, which was reassuring. Surprisingly for question 8, “I know where to get medical care when the doctor’s office is closed” only 40% of patients and 40% of caregivers answered with a “2”. PNP expected 100% of these answers to be scored a “2” since discussions have been had in the past with each of these patients on where and how to seek medical care, through the emergency room.

Discussion

Summary

The QI Project was well received by the caregivers and patients. The readiness assessment survey questions were easy to answer and prompted meaningful discussion during the clinic visits. A total of five patients and their caregivers were included in the QI project. Eighty percent of patients had an improvement in their readiness assessment score. Only one patient did not improve in their readiness assessment score. All caregivers had an increase in readiness assessment scores. For the first PDSA, it was not established quantitatively if the patient’s and caregiver’s readiness assessment scores improved. Both patients responded yes to all four satisfaction survey questions inferring they found the visit useful. With all the participants discussion of topics guided by the readiness assessment survey improved transition readiness. Clinic visits lasted slightly longer than the hour allotted for each visit. The longest visit was due to a caregiver attending that typically did not accompany this particular patient to the clinic visits over the years and therefore more time was spent reviewing details of the medical history.

Interpretation

The Got Transition Six Core Elements of Health Care Transition (https://www.gottransition.org/six-core-elements/transitioning-youth-to-adult/transition-readiness.cfm) can help guide the PNP to assess readiness to transfer to an adult model of care in pediatric patients with hydrocephalus by using questions scored with a “1 – I want to learn” to guide the education intervention during a clinic visit.

A pilot quality improvement project done in a large academic center in the Midwest used a similar approach to the assessment of readiness for transition care and successfully transitioned three patients to an adult model of care by the end of their project (Johnson, A., et. al., 2021).

Limitations

A limitation of the project was the short time frame available to do the project after IRB approval leading to a small number of patients and caregivers assessed. The post-clinic assessment was completed immediately after the clinic visit with the pediatric nurse practitioner present in the clinic room which may have influenced patients' and caregivers' scores. This QI project did not have a formal check to see if patients actually made appointments with an adult neurosurgery provider. With telemedicine visits increasing in demand, this QI project could have included more patients if PNP team was prepared to administer the transition readiness assessment survey remotely.

Conclusion

This quality improvement project initiated a structured formal process for the transition of care using the Got Transition Six Elements of Health Care Transition during a clinic visit with the PNP. Providing readiness assessment for patients and caregivers can help guide the PNP's efforts to set the patient up for a successful transition to an adult model of care with goals of maximizing their independence as they transition out of a pediatric model of healthcare. The next steps for this project include incorporating the rest of the Six Elements of Health Care Transition to continue to promote and support a successful transition of care in the pediatric hydrocephalus population in addition to integrating this process with the electronic health medical record.

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Appendices

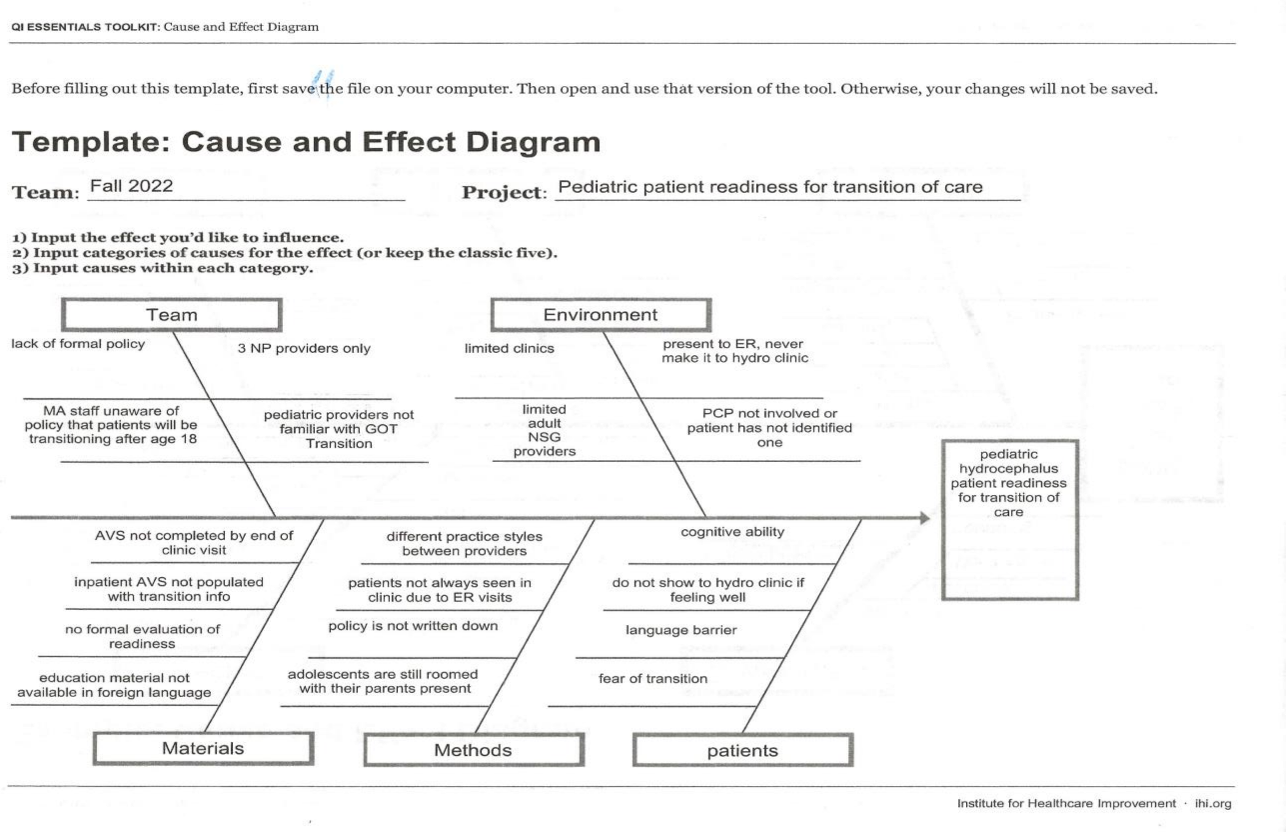
Appendix A

Project Timeline: Evaluate Transition Readiness

	Sept	Dec	Jan	Feb	Mar	Apr	May
Project Planning Nurs 703A	X						
Complete IRB determination 703A		X					
PDSA Cycle 1 703B			X				
PDSA Cycle 2 703B				X			
Final Data Analysis 703B					X		
Write Final Paper 703B						X	
Prepare for project dissemination 703B							X

Appendix B

Assessment Readiness Cause and Effect



QI ESSENTIALS TOOLKIT: Cause and Effect Diagram

Before filling out this template, first save the file on your computer. Then open and use that version of the tool. Otherwise, your changes will not be saved.

Template: Cause and Effect Diagram

Team: Fall 2022

Project: Pediatric patient readiness for transition of care

1) Input the effect you'd like to influence.
2) Input categories of causes for the effect (or keep the classic five).
3) Input causes within each category.

Team
lack of formal policy
3 NP providers only
MA staff unaware of policy that patients will be transitioning after age 18
pediatric providers not familiar with GOT Transition

Environment
limited clinics
present to ER, never make it to hydro clinic
limited adult NSG providers
PCP not involved or patient has not identified one

pediatric hydrocephalus patient readiness for transition of care

AVS not completed by end of clinic visit
inpatient AVS not populated with transition info
no formal evaluation of readiness
education material not available in foreign language
Materials

different practice styles between providers
patients not always seen in clinic due to ER visits
policy is not written down
adolescents are still roomed with their parents present
Methods

cognitive ability
do not show to hydro clinic if feeling well
language barrier
fear of transition
patients

Institute for Healthcare Improvement · ihi.org

Appendix C

Readiness Assessment Survey for Patients/ Score sheet

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	☐ 0	☐ 1	☐ 2
I know how to ask questions when I do not understand what my doctor says.	☐ 0	☐ 1	☐ 2
I know my allergies to medicines.	☐ 0	☐ 1	☐ 2
I know my family medical history.	☐ 0	☐ 1	☐ 2
I talk to the doctor instead of my parent/caregiver talking for me.	☐ 0	☐ 1	☐ 2
I see the doctor on my own during an appointment.	☐ 0	☐ 1	☐ 2
I know when and how to get emergency care.	☐ 0	☐ 1	☐ 2
I know where to get medical care when the doctor's office is closed.	☐ 0	☐ 1	☐ 2
I carry important health information with me every day (e.g., insurance card, emergency contact information).	☐ 0	☐ 1	☐ 2
I know that when I turn 18, I have full privacy in my health care.	☐ 0	☐ 1	☐ 2
I know at least one other person who will support me with my health needs.	☐ 0	☐ 1	☐ 2
I know how to find my doctor's phone number.	☐ 0	☐ 1	☐ 2
I know how to make and cancel my own doctor appointments.	☐ 0	☐ 1	☐ 2
I have a way to get to my doctor's office.	☐ 0	☐ 1	☐ 2
I know how to get a summary of my medical information (e.g., online portal).	☐ 0	☐ 1	☐ 2
I know how to fill out medical forms.	☐ 0	☐ 1	☐ 2
I know how to get a referral if I need it.	☐ 0	☐ 1	☐ 2
I know what health insurance I have.	☐ 0	☐ 1	☐ 2
I know what I need to do to keep my health insurance.	☐ 0	☐ 1	☐ 2
I talk with my parent/caregiver about the health care transition process.	☐ 0	☐ 1	☐ 2

Appendix D

Health Information Summary

FILLABLE_Medical_Summary_Transitioning_Hydrocephalus_Patients_FINAL.pdf

Appendix E

Transitions of Care After Clinic Visit Satisfaction Survey

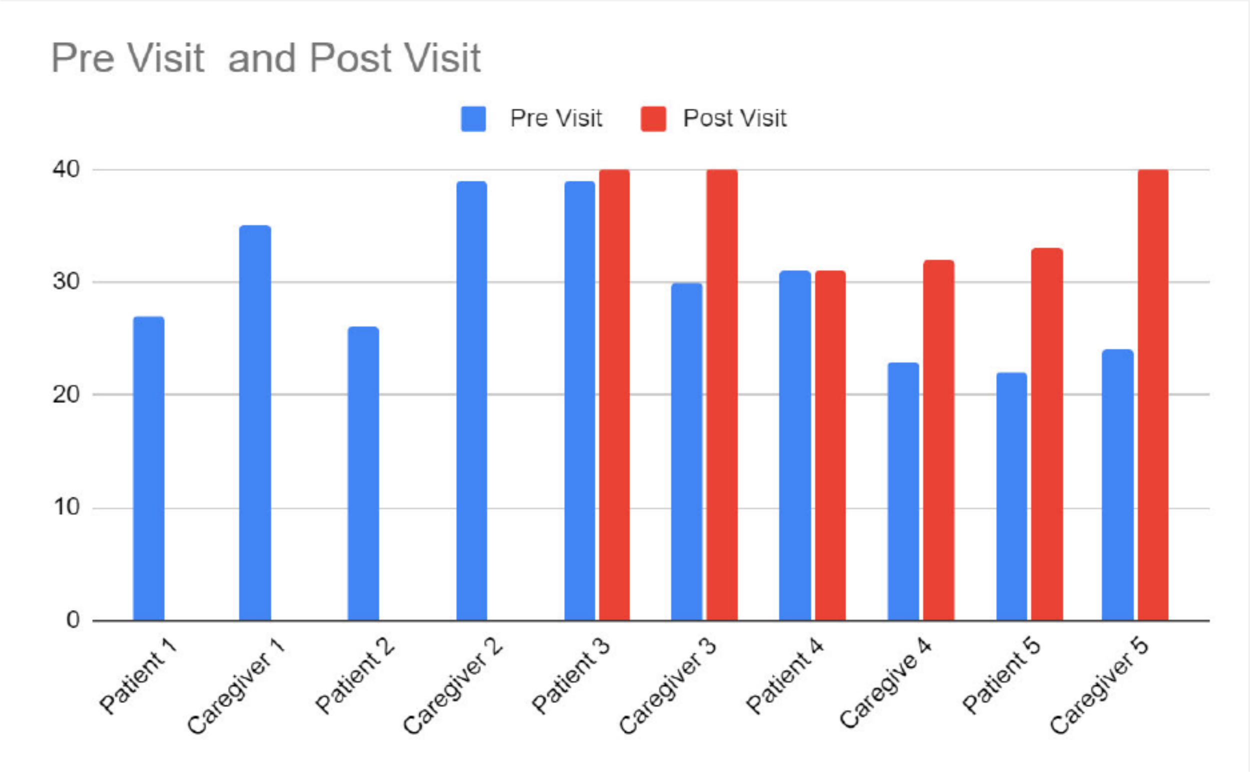
Please answer the following questions

This will help improve our transition process

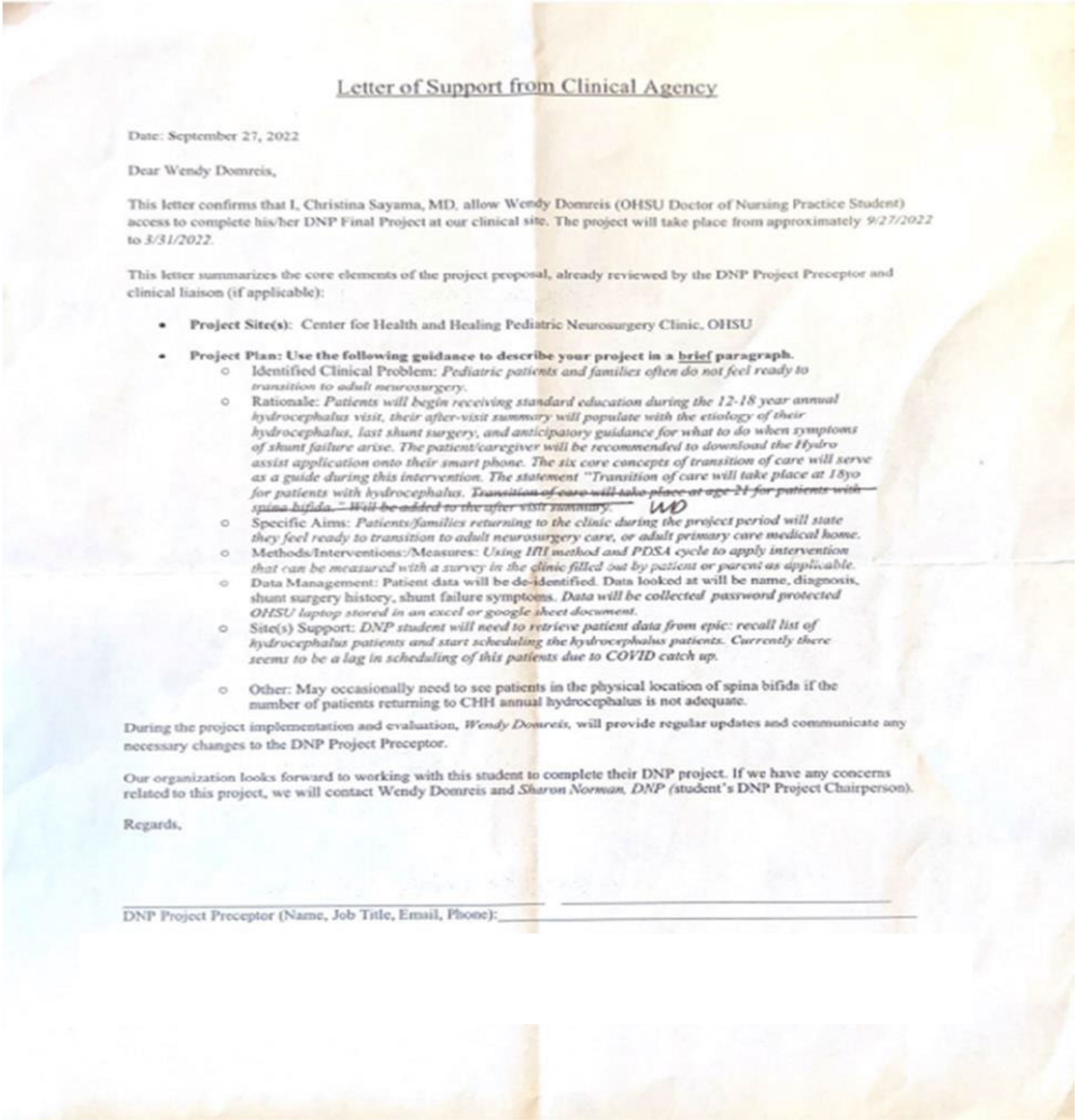
1. Did the provider explain the transition process in a way that you could understand? YES OR NO
2. Explain the age at which you need to transition. YES OR NO
3. Create and share a medical summary with you? YES OR NO
4. Do you have any suggestions regarding the transition process? YES OR NO

Appendix F

Results of the Assessment Survey



Appendix G



Letter of Support from Clinical Agency

Date: September 27, 2022

Dear Wendy Domreis,

This letter confirms that I, Christina Sayama, MD, allow Wendy Domreis (OHSU Doctor of Nursing Practice Student) access to complete his/her DNP Final Project at our clinical site. The project will take place from approximately *9/27/2022* to *3/31/2022*.

This letter summarizes the core elements of the project proposal, already reviewed by the DNP Project Preceptor and clinical liaison (if applicable):

- **Project Site(s):** Center for Health and Healing Pediatric Neurosurgery Clinic, OHSU
- **Project Plan: Use the following guidance to describe your project in a brief paragraph.**
    - Identified Clinical Problem: *Pediatric patients and families often do not feel ready to transition to adult neurosurgery.*
    - Rationale: *Patients will begin receiving standard education during the 12-18 year annual hydrocephalus visit, their after-visit summary will populate with the etiology of their hydrocephalus, last shunt surgery, and anticipatory guidance for what to do when symptoms of shunt failure arise. The patient/caregiver will be recommended to download the Hydro assist application onto their smart phone. The six core concepts of transition of care will serve as a guide during this intervention. The statement "Transition of care will take place at 18yo for patients with hydrocephalus.* ~~*Transition of care will take place at age 21 for patients with spina bifida." Will be added to the after visit summary.*~~ WD
    - Specific Aims: *Patients/families returning to the clinic during the project period will state they feel ready to transition to adult neurosurgery care, or adult primary care medical home.*
    - Methods/Interventions:/Measures: *Using IHI method and PDSA cycle to apply intervention that can be measured with a survey in the clinic filled out by patient or parent as applicable.*
    - Data Management: Patient data will be de-identified. Data looked at will be name, diagnosis, shunt surgery history, shunt failure symptoms. *Data will be collected password protected OHSU laptop stored in an excel or google sheet document.*
    - Site(s) Support: *DNP student will need to retrieve patient data from epic: recall list of hydrocephalus patients and start scheduling the hydrocephalus patients. Currently there seems to be a lag in scheduling of this patients due to COVID catch up.*

    - Other: May occasionally need to see patients in the physical location of spina bifida if the number of patients returning to CHH annual hydrocephalus is not adequate.

During the project implementation and evaluation, *Wendy Domreis,* will provide regular updates and communicate any necessary changes to the DNP Project Preceptor.

Our organization looks forward to working with this student to complete their DNP project. If we have any concerns related to this project, we will contact Wendy Domreis and *Sharon Norman, DNP (*student's DNP Project Chairperson).

Regards,

DNP Project Preceptor (Name, Job Title, Email, Phone):______________________

Appendix H

LETTEROFDETERMINATION.docx

NOT HUMAN RESEARCH
January 11, 2023

Dear Investigator:
On 1/11/2023, the IRB reviewed the following submission:
Title of Study: Assessing Transition Readiness in Pediatric hydrocephalus patients
Investigator: Sharon Norman

IRB ID: STUDY00025274
Funding: None
The IRB determined that the proposed activity is not research involving human subjects. IRB review and approval is not required.
Certain changes to the research plan may affect this determination. Contact the IRB Office if your project changes and you have questions regarding the need for IRB oversight.
If this project involves the collection, use, or disclosure of Protected Health Information (PHI), you must comply with all applicable requirements under HIPAA. See the HIPAA and Research website and the Information Privacy and Security website for more information.
Sincerely,

The OHSU IRB Office