Measuring Transition Needs of Pediatric Patients with Bleeding Disorders

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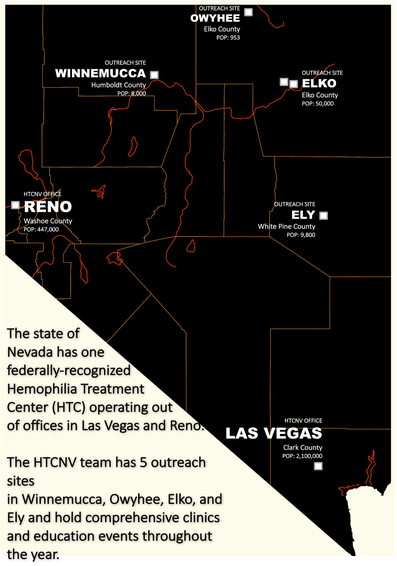
Hemophilia Treatment Center of Nevada (HTCNV)

ABOUT US



The state of Nevada has one federally-recognized Hemophilia Treatment Center (HTC) operating out of offices in Las Vegas and Reno.

The HTCNV team has 5 outreach sites in Winnemucca, Owyhee, Elko, and Ely and hold comprehensive clinics and education events throughout the year.

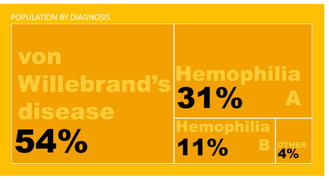
PURPOSE

The HTCNV is committed to comprehensive, patient-centered care for the bleeding disorder community throughout the lifespan.

PATIENTS

- The HTCNV is a standalone lifespan center.
- Over 1,100 established patients (2017)
- Average comp clinic time: 90 minutes

POPULATION BY DIAGNOSIS



PROFESSIONALS

DR. ALAN IKEDA, MD — *MEDICAL DIRECTOR & GRANT PI, LAS VEGAS*
AMBER FEDERIZO, APRN — *NURSE PRACTITIONER, LAS VEGAS*
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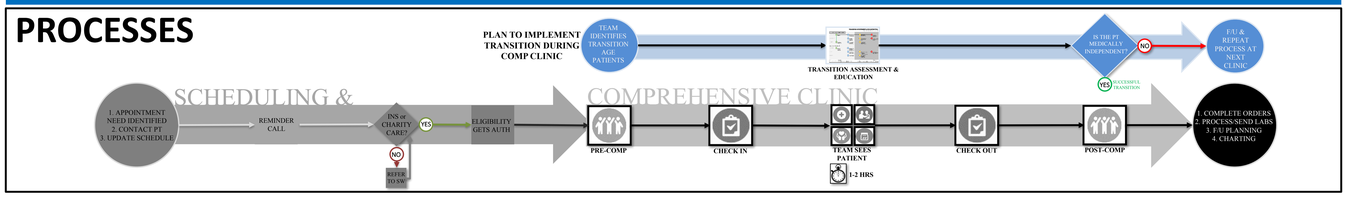
REBECCA BERKOWITZ, RN — *RN COORDINATOR & GRANT PI, RENO*
JR DYER, RN — *REGISTERED NURSE, LAS VEGAS*
LISA CERVANTES, MA — *MEDICAL ASSISTANT & DATA MANAGER, RENO*
OFELIA BARRERA, MA — *MEDICAL ASSISTANT, LAS VEGAS*
KEVIN TRAN — *PHARMACY TECHNICIAN, LAS VEGAS*

THE HTCNV DOES BUSINESS UNDER THE NON-PROFIT 501(c)(3),
ALLIANCE FOR CHILDHOOD DISEASES
CURE 4 THE KIDS FOUNDATION
CHILDREN'S SPECIALTY CENTER OF NEVADA
HEMOPHILIA TREATMENT CENTER OF NEVADA

PROBLEM IDENTIFICATION & DEFINITION

- **Transition**, defined as *the **purposeful & planned process of educating patients to competently manage their own chronic conditions***, is a topic of vital importance to the HTCNV's lifelong comprehensive care model.
- Approximately **45%** of the HTCNV's patients are between the ages of **10-19 years old**. In the context of this age group, **transition needs** are measured by the practical knowledge and skills of HTCNV's adolescent patients to successfully manage their own care in adulthood.
- The HTCNV **did not previously have any formal processes in place to measure its patients' transition needs**.
- In concert with other HTCs nationwide, the Dartmouth Institute Microsystem Academy (TDIMA) was selected by the National Hemophilia Program Coordinating Center (NHPCC)'s Quality Improvement (QI) initiative as the standardized system to focus on transition.

PROCESSES



GLOBAL AIM

WE AIM TO IMPROVE ADOLESCENT TRANSITIONING IN OUR COMPREHENSIVE CLINIC. THE PROCESS BEGINS WITH IDENTIFYING AND ASSESSING TRANSITION NEEDS. THE PROCESS ENDS WITH SUCCESSFUL TRANSITION. BY WORKING ON THE PROCESS, WE EXPECT TO ACHIEVE MEDICAL INDEPENDENCE FOR

SPECIFIC AIM

WE WILL INCREASE THE NUMBER OF ASSESSMENTS OF TRANSITION-AGE PATIENTS COMPLETED FROM 0-20 BY JUNE 1ST.

PDSA 1.1

The first draft of the Transition Tool was a 4-page questionnaire.

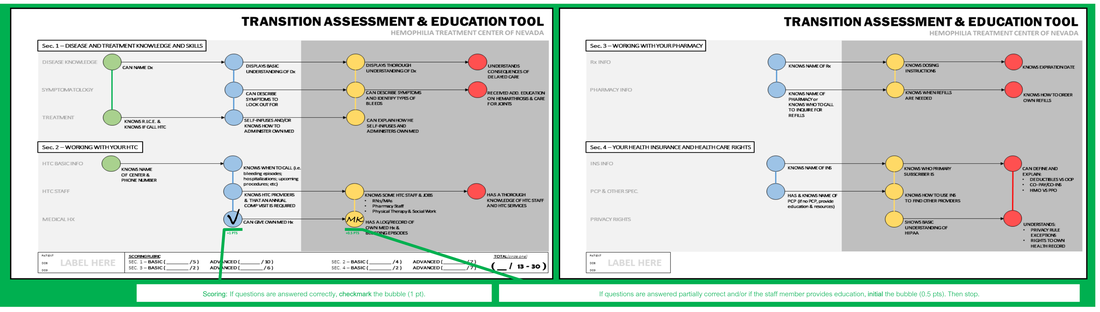
GOAL: Complete four Transitioning Assessments between 03/07/17 to 04/11/17.

RESULTS: From 03/07/17 to 04/11/17, the HTC team completed seven Transitioning Assessments.

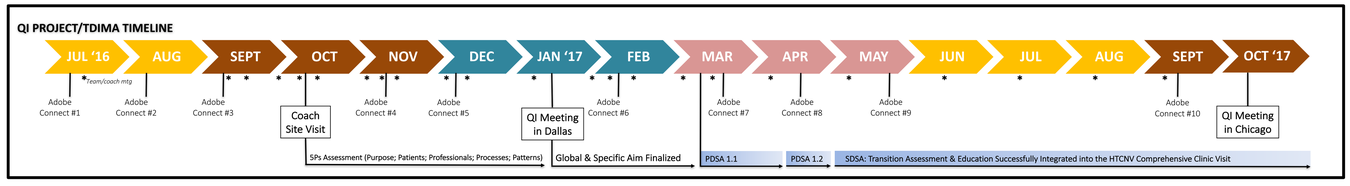
OBSERVATIONS:

- The process was simple to teach and understand, but **difficult to implement**. The tool was cumbersome to use.
- Patients don't care to take the assessment tool home.
- The answers acquired were **difficult to score** and did not help gauge a patient's transition level.
- There was **no differentiation between different levels of education needed** relative to the severity or complexity of diagnosis.

PDSA 1.2 ➡ SDSA



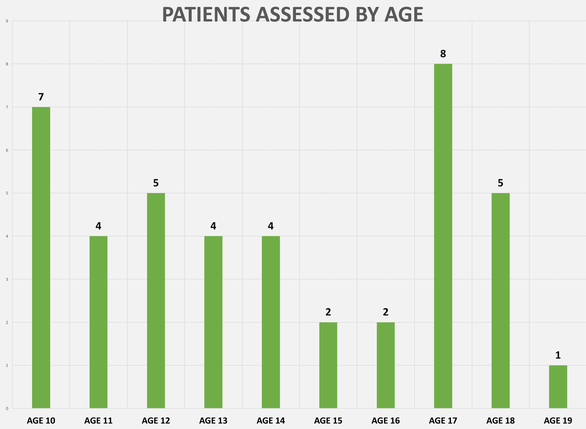
QI PROJECT/TDIMA TIMELINE



FINDINGS

DATA COLLECTION PERIOD
04/11/17– 05/16/17
(6 weeks)

PATIENTS ASSESSED
39/42
94%

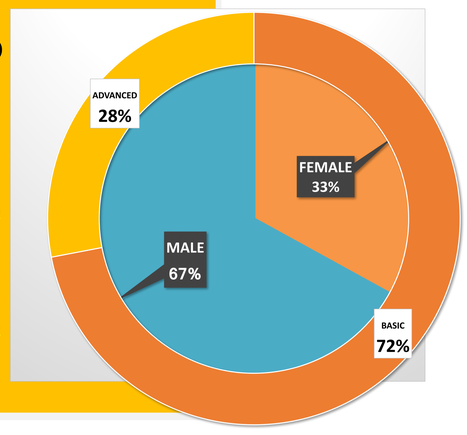


EDUCATION TAILORED TO THE SEVERITY OF DIAGNOSIS AND/OR SYMPTOMATOLOGY

BASIC vs. ADVANCED

72%
13/28 FEMALES
VWD (11)
MILD FVIII (1)
OTHER (1)
15/28 MALES
DSP (2)
VWD (13)

28%
0/11 FEMALES
11/11 MALES
MOD. FVIII (9)
SEV. FVIII (2)



RESULTS

- Increased staff awareness of our patient population's transition needs
- Developed and implemented a center-specific Mission Statement which lead to our development of a center-specific Transition tool for patients with bleeding disorders aged 10-19
- Successful implementation of the transition tool within our comprehensive clinic has allowed us to better understand our patients' transition needs and provide them, and their families, optimal care

LESSONS LEARNED

- Utilizing our PDSA 1.1 with a small patient population allowed us to improve on the process and define a more improved aim and determine a measurable outcome to develop a our PDSA 1.2 transition tool
- The collaborative process of using effective meeting skills to strengthen our working relationships has helped to strengthen our team and allow for effective communication amongst one another
- Provided our center with the knowledge and framework of QI and how this can be applied to our patient population and how it may relate to future QI efforts within our organization

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