Evaluation of transition of care for patients with disabilities within the Lehigh Valley

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Evaluation of transition of care for patients with disabilities within the Lehigh Valley

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Background

- Patients with Intellectual Disabilities (ID) often have poor health outcomes as the result of subpar health care[4].
- These patients are subjected to inadequate attention to care needs and health promotion, and decreased access and quality of care[4].
- Patients with intellectual and developmental disabilities are at greater risk of perceiving their health as poorer when compared to patients without disabilities, despite similar risk factors for poor health[3].
- Advances in medicine have allowed patients with ID to live longer, and they are now faced with a new challenge: transitioning care from the pediatric clinics to the adult medicine clinics[1].
- There is increased need for comprehensive care for patients with ID, and enhanced handoffs from pediatric to adult care[4].
- LVHN is not immune to these issues.
- While it does have a pediatric Complex Care Clinic located at its 17th and Chew Street location, many of the adult medicine clinics have challenges with both physical access and provider knowledge regarding patients with disabilities[2].
- Without a standard procedure for the transition of care from the Complex Care Clinic to the adult medicine practices, patients with ID at the Lehigh Valley Health Network are subject to the disparities and outcomes seen in other patients with disabilities[4].

Problem Statement

This project attempts to elucidate the current practices in place to transition care, patient experiences and fears regarding those practices, and create a vision for a new clinic designed to transition patients with ID at LVHN.

Methods

Clinic Design

- Initial clinic designs were discussed and created with Dr. Jain.
- These were taken to meetings with LVPG Senior Vice President of Operations, Mr. James Demoupolos, during which site locations were discussed as well as modifications to design.
- Further modifications were made in meeting with LVPG Director of Operations Molly Thompson Chavez.

Patient Interviews

Pre-Transition

- Patient names were selected from a registry of patients greater than 14 years of age with diagnoses of intellectual disability and global developmental delay.
- Patients had to have been seen at the LVPG Pediatrics Complex Care Clinic at 17th St and Chew on or after 01/01/2018.
- Patients were asked to participate in focused interviews regarding their upcoming transition from pediatrics to adult medicine.
- Patients were also asked to rate their preparation for transitioning on a scale of 1-5.

Post-Transition

- Patient names were selected from a registry of patients 18-24 years of age with diagnoses of intellectual disability and global developmental delay.
- Patients had to have been seen at LVHN Family Medicine Teaching Clinics on or after 01/01/2018. Family Medicine practices used were: Family Health Center, Easton Ave, NHCLV, and Hamburg.
- Patients were asked to participate in focused interviews regarding their transition from pediatrics to adult medicine.
- Patients were also asked to rate their preparation for transitioning on a scale of 1-5.

Results

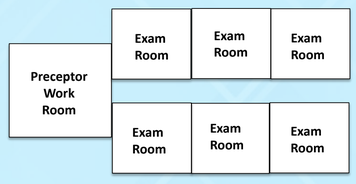
Clinic Design

- Initial meeting to discuss clinic structure and design yielded idea presented in Figure 1a.
- Family Medicine and pediatric providers, as well as care coordinators, nutritionists, and therapists will be based in the precepting room to discuss individual cases.
- The clinic was designed so the pediatric team, the adult team, and other providers would see each patient concurrently.
- Handoff design is shown in Figure 1b.

Patient Interviews

- Of the 25% of pre-transition patients who had discussed transitioning, it was noted that they "were told it is time to start thinking about transitioning to adult providers".
- None of the pre-transition patients were aware of if or how their pediatricians would communicate with adult medicine providers, or if there were to be handoffs between the providers.
- 75% of patients discussed transition to adult providers with their pediatrician prior to leaving the pediatricians practice.
- Those patients were given names of potential providers and told to look into the suggested practices. Patients noted the transition period to be strenuous and difficult, one family stating they switched adult providers multiple times looking for "someone who would look at [the patient]".
- 50% of patients were unsure if there was any communication between pediatric and adult providers. No patients were aware of face-to-face meetings between adult and pediatric providers, though 50% noted phone conversations.

a.



b.

Figure 1. Initial design for comprehensive medical home style clinic for patients with disabilities. a: Clinic structure. Designed with preceptor work room for coordination between care team members and exam rooms. Designed with primary pre-transition patients on one side of hall and primary family medicine patients on the opposite side. b. Clinic structure based on warm resident handoff model. Designed to have Pediatric PGY1 to maintain primary care for duration of residency, handing off to PGY1 Family Medicine resident during PGY3 year. The FM PGY1 then takes over as primary care provider for duration of residency.

	Pre-Transition Patients (Pediatrics)	Post-Transition Patients (Family Medicine)
Average Transition Age	22 (anticipated)	18.25
Average Years Loss of Follow Up During Transition	n/a	0.25
Average Number of Specialists	6	4.75

Table 1. Patient data. Pre-transition patients anticipated transitioning at an average age of 22 years. Post-transition patients transitioned at an average age of 18.25 years. Post-transition patients had an average loss of follow up time of 0.25 years during transitioning. Average number of specialists seen by patients in the pre- and post-transition patients was 6 and 5 respectively.

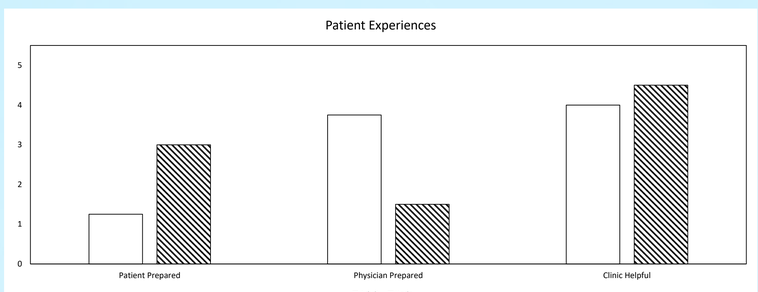


Figure 2. Patient experiences and expectations about transitioning. Patients were asked to rate on a scale of 1 to 5 how prepared they were/are for transitioning, how prepared their adult physicians were/are to handle their medical conditions, and whether or not the proposed clinic would be beneficial to the transition process. Post-transition patients reported themselves not being prepared to transition (1.25/5), but physicians were prepared to receive them (3.75/5). Pre-transition patients reported feeling prepared to transition (3/5) but were not confident in adult providers' preparedness (1.5/5). Both pre-transition (4.5/5) and post-transition (4/5) patients reported that they would benefit from a transitional clinic.

Discussion

- There was a large discrepancy between the expected age of transition in the pre-transition grouping (22 years average) compared with the actual age of transition for the post-transition patients (18.25 years)
- It is concerning that 75% of the pre-transition patients in this study had yet to have a conversation with their provider about transitioning, considering it has been suggested that patients should start transitioning at 12-16 years of age[7-9]
- Despite this, post-transition patients are satisfied with their current adult providers, which contrasts with the expectations of pre-transition patients when considering finding adult care providers
- Pre-transition patients were confident in their preparation, while post-transition patients reflected that they were unprepared to transition
- The transitional care clinic model proposed here was rated highly by interviewed patients in both pre- and post-transition groups
- SELECT Competencies
  - Leadership: Designing a clinic from scratch requires taking a leadership role and interacting with healthcare leadership
  - Health Systems: We proposed a clinic in the medical home model, and incorporated an interdisciplinary team to help improve two corners of the iron triangle for patients with ID: quality and access to care
  - VBPCC: The project tries to consolidate care to one location and thus reduce the hassle of multiple appointments in many locations for patients
- The major limitation of the project was the low response rate to interview requests
- Moving forward, data gathering with surveys at the involved clinics would provide more data
- Additionally, a pilot study of using a medical home model for patients with disabilities can be incorporated at LVHN FM Residency Clinics.

Conclusions

- While transitioning care from pediatric to adult primary care, patients with disabilities within the Lehigh Valley Health Network struggle to find providers who meet their complex needs
- While they can find providers who they feel comfortable with, the process of doing so is stressful and can result in loss of follow up for extended periods of time
- Patients who have already transitioned felt they were not prepared to do so prior to leaving their pediatrician's office
- Proposed here is a clinic designed in the medical home model with the goal of providing quality, efficient transition of care from pediatric to adult primary care medicine.
- Other measures that can be incorporated into the proposed model include using the ADAPT survey, or a modified ADAPT survey for patients with disabilities, the Surrey Place Healthcare Transfer Tool and SHARE Transition Checklist[5-6]

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