

2-3-2023

Health Care Provider's Perceptions of the Transition Between Pediatric to Adolescent and Adulthood: A Qualitative Inquiry

Antoinette W. Coward

Prairie View A&M University, ancoward@pvamu.edu

Andrea E. McDonald

Prairie View A&M University, aemcdonald@pvamu.edu

Follow this and additional works at: <https://digitalcommons.pvamu.edu/jramp>



Part of the [Education Commons](#), [Health Services Administration Commons](#), [Health Services Research Commons](#), and the [Public Health Education and Promotion Commons](#)

Recommended Citation

Coward, A. W., & McDonald, A. E. (2023). Health Care Provider's Perceptions of the Transition Between Pediatric to Adolescent and Adulthood: A Qualitative Inquiry. *The Journal of the Research Association of Minority Professors*, 25(1). Retrieved from <https://digitalcommons.pvamu.edu/jramp/vol25/iss1/2>

This Article is brought to you for free and open access by Digital Commons @PVAMU. It has been accepted for inclusion in The Journal of the Research Association of Minority Professors by an authorized editor of Digital Commons @PVAMU. For more information, please contact hvkoshy@pvamu.edu.

Health Care Provider's Perceptions of the Transition Between Pediatric to Adolescent and Adulthood: A Qualitative Inquiry

INTRODUCTION

According to the U.S. Department of Health and Human Services (HHS), the health care transition from pediatric to adult health care for adolescents with and without special health care needs is a recognized maternal and child health need (HHS, 2019). Health care transition from pediatric to adult health services prepares children from 12 to 17 years of age with the capacity to be independent and to move from a child-oriented clinical setting to an independent or self-responsible setting (Rutishauser et al., 2014; Kerr, et al., 2020). Few studies have suggested that the life expectancies among children with special needs have increased, thus the recognition of health care transition is crucial due to the increased diagnosis of developmental conditions in children, chronic health issues, and survival rate (Lemly, et al., 2013; Webb et al., 2015; Friedberg, et al., 2017). Appropriate health care transition models are needed in medical homes to establish activities for continuity of care to reduce unnecessary hospitalization, poor health outcomes, and gaps in health insurance coverage for adolescents with special health care needs (Public Health and Welfare Act, 2008; Feeney et al., 2021).

Health Care Transition Models

Prior models developed and implemented, show positive outcomes during the transition. For instance, the Six Core Elements of Health Care Transition is a nationally recognized and tested model that includes a broad application of transition and behavioral health care (McManus & White, 2017; Fleary, et al., 2018). The Association of Maternal and Child Health Programs (AMCHP, 2016) introduced the Six Core Elements of Health Care Transition as a best practice for maternal and child health, along with the clinical health care transition physician algorithm.

These programs incorporate the Six Core Elements of Health Care Transition into the standard patient flow for adolescents with special health care needs and highlighted successful patient transfers and sustainable systematic transition planning (Jones et al., 2017; McManus et al., 2015).

Medical home health care transition programs should promote self-care management in adult health systems (Cleverley et al., 2018; De Marchis et al., 2019). Federally Qualified Health Care Centers (FQHCs) are community health care with federal funds to service local neighborhood throughout America. Currently, FQHCs are the primary medical home for over 30 million people in more than 13,000 rural and urban communities. Approximately 85% of the FQHC medical directors reported benefits from health care transition compared to non-provider clinical staff (55%). Also, forty-six percent of medical directors indicated the inclusion of the leadership and staff of FQHCs in the decisions and implementation of new ideas pertaining to health care transition (Quinn et al., 2013; Roy, Valdez, et al., 2022). Populations with special health needs or conditions are complex and closing the gap between clinical skills practices and adolescents' abilities can improve patient outcomes (Wells & Manning, 2017).

The purpose of this study was to determine how the current transition practices from pediatric to adult health care strengthen adolescents with special health care needs at FQHCs in Maryland and Delaware in alignment with the Six Core Elements of Health Care Transition.

METHODS

This qualitative study uses a phenomenology approach to understand and interpret FQHC medical directors' experiences and perceptions of health care transition from pediatric to adult health care. According to Creswell and Creswell (2018), phenomenological research focuses on an individual's live experiences and perceptions of the world. The approach sought to understand

the meaning of interactions and events affecting people in any given community or culture. We used a purposive sampling approach to recruit medical doctors. After approval from the university Institutional Review Board (IRB) was received, we first sent letters to the Mid-Atlantic Association of Community Health Centers to recruit FQHC medical directors in Maryland and Delaware through letters and flyers. All the recruitment materials were in English only, as providers had to speak English to assume their role. Seventeen (n=17) potential participants responded to the emails. A screening instrument with demographic information was sent to all the participants. The eligibility criteria include 1) a medical director at a satellite site and 2) the headquarters or from the associated FQHC.

The medical directors were asked to participate in a semi-structured interview with open-ended questions. These questions allowed the medical directors to express their thoughts and experiences about the transition process from childhood to adolescence. During the interview sessions, a trained qualitative moderator facilitated each session with one notetaker. This approach allows the researchers to ensure accurate data collection, transcription, and documentation of participants' responses. Each interview lasted approximately 20 minutes and was audio recorded using a digital recorder.

Immediately after each session, the lead investigators transcribed the data verbatim and two researchers read the transcript independently and compared it against the audio recordings. The coding process began with each researcher creating a codebook. The coding process continued for the first four transcripts, and afterward, minor revisions were made to the terminology of some codes. After this, weekly meetings were scheduled to identify common themes and definitions. Whenever discrepancies occurred, deliberation continued until a consensus was met. The coders' inter-rater reliability (.89 or 89%) was measured per Landis and

Koch (1977). Two or more similar codes eventually constitute a theme. An audit trail was maintained to explain how the results were obtained, specifically the research procedures, interviewer observations, challenges, and facilitators during the study.

RESULTS

Participant's characteristic

The sample consisted of 10 medical doctors who self-identified as male (n=3) and female (n=7). Each acknowledged serving in the capacity of a director, of which seven (n=7) were pediatricians, and three (n=3) family practice providers. Two (n=2) were assistant medical directors, two (n=2) chief medical directors, and six (6) satellite medical directors. The medical directors reported working at their respective institutions from 4 months to over six years.

Table 1 Summary of Participants Worked at each Institution

Years	Medical Doctors
I or less	5
2 - 5 years	1
6 years or higher	4

Note: Medical Director Health Care Transition Interview, 2020

All the participants indicated their roles as a director and experiences with transition varied. The participants explained that their role includes policy development and incorporating standards such as health care transition. Three (n= 3) of participants highlighted other roles such as organizing and implementing standards. Four (n=4) focused on maintaining medical care records, and three (n=3) on advocacy for health policy. Three major themes emerged from our interview. These include education, limited transitional practice between care, and organizational infrastructure.

Table 1: Barriers and facilitators to the implementation of the six core elements of health care transition

Themes	Quotes
Education/Training	<ul style="list-style-type: none"> • <i>“A lack of knowledge and education is present about the six core elements of health care transition from pediatric to adult health care; however, familiarity is lacking on the elements and entire process.”</i> • <i>“Training and education for FQHC leadership, staff and board members on health care transition, transition reimbursement, and revenue. Many medical directors believe the focus of their role is primary care gatekeepers of patients and families, and at age 18, there may be a hand-off to another provider.”</i> • <i>“Offer education to build doctors’ relationships with patients and families to discuss health care transition planning.”</i>
Limited Transitional Practices Between Care	<ul style="list-style-type: none"> • <i>“Clinicians are aware of the six core elements of health care transition, but they are not familiar with its process and functionality.”</i> • <i>“We do not use the six core elements of health care transition and only some transition planning, transfer of care, and transfer completion is implemented”</i> • <i>“Of all the FQHC standard requirements, the six core elements of health care transition is not included.”</i>
Organizational Infrastructure	<ul style="list-style-type: none"> • <i>“What is practiced of the six core elements of health care transition is limited, and the focus is on the transfer of care. Presently, what is practiced is transfer of care and transfer completion in FQHCs.”</i> • <i>“Systems to recognize adolescents with special health care needs and other resources must be in place to support the ability to address the full range of the six core elements of health care transition.”</i> • <i>“Evidence-based models and a dedicated person to implement a health care transition process would determine the reality of missing components such as policies, readiness measures, and tracking.”</i>

Education and Training

Education emerged in all interviews. The participants indicated that they were aware of the six core elements of health care transition but nine of ten indicated that they are unaware of all the processes and functionality. All ten medical directors believed that more education and training are needed regarding the six core elements of health care transition. Yet, only two medical directors believe the six core elements of health care transition might reduce health challenges and disparities among patients. Eight of the ten medical directors indicated that training all the staff about the transition process could help with the implementation. All participants believed that promoting the core elements can help build patient relationships and promote better health outcomes. Three medical directors stated,

“A lack of knowledge and education is present about the six core elements of health care transition from pediatric to adult health care; however, familiarity is lacking on elements and the entire process (P#9).”

“Offer education to build doctors’ relationships with patients and families to discuss health care transition planning (P#5).”

“Clinicians are aware of the six core elements of health care transition, but they are unfamiliar with its process and functionality P#3.”

Limited Transitional Practice Between Care

Understanding the transition between adolescence and adulthood health care transition is essential. During the interviews, eight directors mentioned that FQHCs do not use all six core elements of health care transition, while some utilize transition planning, transfer of care, and transfer completion. Two of the directors stated that their administration does not require them to utilize the six core elements. Instead, they move the patients forwards based on the pediatric

board and their age. For example, a child can reach the age of eighteen but is not capable of functioning independently. One provider stated:

“We do not use the six core elements of health care transition and only some transition planning, transfer of care, and transfer completion is implemented (P#4).”

Organizational Infrastructure

Several participants stated that the lack of transition models, policies, and standards for implementing the health care in FQHCs are a problem. The medical directors mentioned that they are required to fulfill all FQHC mandated requirements, which does not include the six core elements of health care transition. They believed that the electronic medical record tools are needed to coordinate with existing systems to track smooth transition and continuity of care for adolescents to adulthood.

“The practiced of the six core elements of health care transition is limited and our main focus is on transfer of care (P#1).”

The participants suggested that it is necessary to facilitate health care transition as a required federal standard for FQHC which must be approval by board members. Also, they recommended including a defined procedures and protocols with a matrix of care and pilot programs critical to the six core elements.

“Evidence-based models and a dedicated person to implement a health care transition process would determine the reality of missing components such as policies, readiness measures, and tracking (P#4).”

“Systems to recognize adolescents with special health care needs and other resources must be in place to support the ability to address the full range of the six core elements of health care transition (P#3).”

DISCUSSIONS

This study sought to understand the transitional process between pediatric and adult health care for adolescents with special health care needs at FQHCs. The results of the study found that education and training, minimal transition, and organizational infrastructure are some barriers that limit the full effects of the six core elements of health care transition. Adolescents are at a critical stage of life and should be provided with all the necessary care to build cognitive and physical health.

This study finds that comprehensive health care transition was valued by the medical directors, but authorized FQHC program requirements lack the inclusion of the transition components of the six core elements of transition. The six core elements of health care transition include transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion (Jones et al., 2019). A previous study results showed that health care transition preparedness and health outcomes impacted 83% of youth 12 to 17 years as they are not meeting performance standards (Le Roux et al., 2017; White et al., 2018; HRSA, 2018).

In addition, the medical directors stated the need for dedicated administrators and pilot programs to examine the operationalized transition and matrix of care measures in the organizational infrastructure. Although the medical directors perceived health care transition contributed to positive outcomes for adolescents, the acquirement of resources along with established leadership support is more likely to allow implementation of detailed planning to prepare adolescents for transition to adult health services. Research has found that perception may be positive on a phenomenon such as health care transition, but the advancement of

transition is contingent on the effective use of transition tools to improve adolescent health outcomes (Feeney et al., 2021).

The present study explores the transitional care of adolescence in a federally qualified health care setting. Some key strengths of this study are its qualitative approaches to understanding medical directors' support during patient flow between providers who serve adolescents and young adults. Another strength is that data saturation was reached with the responses to the interview questions. Finally, several important limitations need to be considered. The generalizability of these results is subject to certain limitations. For instance, demographic data revealed that most participants were from satellite location versus headquarter medical directors. Since the chief medical director oversees all satellite facilities, responses from the satellite medical directors might not be representative of the headquarters' operational practices or responses might be personalized. Further research in this field would be of great help with creating a more comprehensive health care transition process.

CONCLUSIONS

The design of this study was to assess the transitional process between pediatric and adult health care. A result found was that a comprehensive health care transition was lacking and did not focus on the entire process. With further development, a comprehensive healthcare transition process is recommended to include the six core elements of healthcare transition which are transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion. Additional research is needed to examine whether similar data would be confirmed with a larger quantitative study and demonstrate statistical significance.

REFERENCES

- Association of Maternal and Child Health Programs. (2016). Sharing best practices in maternal and child health – Using the six core elements of health care transition in Medicaid managed care. Retrieved from <http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/ISDocs/Got%20Transition.pdf#search=got%20transition>
- Cleverley, K., Rowland, E., Bennett, K., Jeffs, L., & Gore, D. (2018). Identifying core components and indicators of successful transitions from child to adult mental health services: A scoping review. *European Child Adolescent Psychiatry, 29*, 109-121. <https://doi.org/10.1007/s00787-018-1213-1>
- Creswell, J. W. & Creswell, J. D. (2018). *Qualitative, quantitative, and mixed methods approaches* (5th ed.). Thousand Oaks, CA: Sage Publication, Inc.
- De Marchis, E. H., Doekhie, K., Willard-Grace, R., & Olayiwola, J. N. (2019). The impact of the patient-centered medical home on health care disparities: Exploring stakeholder perspectives on current standards and future Directions. *Population health management, 22*(2), 99–107. <https://doi.org/10.1089/pop.2018.0055>
- Feeney C., Hotez E., Wan L., Bishop L., Timmerman J., Haley M., Kuo A., Fernandes P. A. (2021). Multi-Institutional collaborative to assess the knowledge and skills of medicine-pediatrics residents in health care transition. *Cureus. 13*(12):e20327. <https://doi.org/10.7759/cureus.20327>

- Fleary, S., Joseph, P., & Pappagianopoulos, J. (2018). Adolescent health literacy and health behaviors: A systematic review. *Journal of Adolescence*, *62*, 116-127.
<https://doi.org/10.1016/j.adolescence.2017.11.010>
- Friedberg, M. W., Reid, R. O., Timbie, J. W., Setodji, C., Kofner, A., Weidmer, B., & Kahn, K. (2017). Federally qualified health center clinicians and staff increasingly dissatisfied with workplace conditions. *Health Affairs*, *36*(8), 1469-1475.
<https://doi.org/10.1377/hlthaff.2017.0205>
- Health Resources Services Administration. (2018, January). Health center program compliance manual. Bureau of Primary Health Care. Retrieved from
<https://bphc.hrsa.gov/programrequirements/compliancemanual/introduction.html>
- Health Resources Services Administration. (2019). National Performance Measures. Maternal and Child Health Bureau. Retrieved from
<https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures>
- Jones, M. R., Hooper, T. J., Cuomo, C., Crouch, G., Hickam, T., Lestishock, L., White, P. H. (2019). Special issue on health care transitions - Evaluation of a health care transition improvement process in seven large health care systems. *Journal of Pediatric Nursing*, *47*, 44-50. <https://doi.org/10.1016/j.pedn.2019.04.007>
- Jones, M. R., Robbins, B. W., Augustine, M., Doyle, J., Mack-Fogg, J., Jones, H., White, P. H. (2017). Transfer from pediatric to adult endocrinology. *Endocrine Practice: Official Journal of the American College of Endocrinology and the American Association of Clinical Endocrinologists*, *23*(7), 822–830. <https://doi.org/10.4158/EP171753.OR>
- Kerr, H., Widger, K., Cullen-Dean, G., Price, J., O'Halloran, P. (2020). "Transition from children's to adult services for adolescents/young adults with life-limiting conditions:

developing realist programme theory through an international comparison". *BMC Palliat Care*. 19(1):115. <https://doi.org/10.1186/s12904-020-00620-2>. PMID: 32731863; PMCID: PMC7393825.

Landis, J. R., Koch, G. G. (1977). "The measurement of observer agreement for categorical data". *Biometric*. 33(1):159-174. <https://www.jstor.org/stable/2529310>; 06-02-2020 17:54 UTC

Le Roux, E., Mellerio, H., Guilmin-Crépon, S., Gottot, S., Jacquin, P., Boulkedid, R., ...Alberti, C. (2017). Methodology used in comparative studies assessing programmes of transition from paediatrics to adult care programmes: A systematic review. *BMJ Open*, 7(7), e012338. <https://doi.org/10.1136/bmjopen-2016-012338>

Lemly, D. C., Weitzman, E. R., & O'Hare, K. (2013). Advancing healthcare transitions in the medical home: Tools for providers, families and adolescents with special healthcare needs. *Current Opinion in Pediatrics*, 25(4), 439-446. <https://doi.org/10.1097/MOP.0b013e3283623d2f>

McManus, M. & White, P. (2017). Transition to adult health care services for young adults with chronic medical illness and psychiatric comorbidity. *Child and Adolescent Psychiatric Clinics of North America*, 26(2), 367–380. <https://doi.org/10.1016/j.chc.2016.12.010>

McManus, M., White, P., Pirtle, R., Hancock, C., Ablan, M., & Corona-Parra, R. (2015). Incorporating the Six Core Elements of health care transition Into a Medicaid managed care plan: Lessons learned from a pilot project. *Journal of Pediatric Nursing*, 30 (Special issue: Health care transition for adolescents and emerging adults with special health care needs and disabilities), 700-713. <https://doi.org/10.1016/j.pedn.2015.05.029>

Public Health and Welfare Act, 42 U.S.C. §254b (2008). Retrieved from

<https://uscode.house.gov/view.xhtml?req=granuleid:USC-prelim-title42-section254b&num=0&edition=prelim>

Quinn, M. T., Gunter, K. E., Nocon, R. S., Lewis, S. E., Vable, A. M., Hui Tang, ... Chin, M. H.

(2013). Undergoing transformation to the patient centered medical home in safety net health centers: Perspectives from the front lines. *Ethnicity & Disease*, 23(3), 356–362.

Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/23914423>

Roy, S., Valdez, A. M., Trejo, B., Bakewell, T., Gallarde-Kim, S., & Martin, A. J. (2022). “All

circuits ended”: Family experiences of transitioning from pediatric to adult healthcare for young adults with medical complexity in Oregon. *Journal of pediatric nursing*, 62, 171-

176. <https://doi.org/10.1016/j.pedn.2021.06.008>

Rutishauser, C., Sawyer, S. M., & Ambresin, A. (2014). Transition of young people with chronic

conditions: A cross-sectional study of patient perceptions before and after transfer from pediatric to adult health care. *European Journal of Pediatrics*, 173(8), 1067-1074.

<https://doi.org/10.1007/s00431-014-2291-9>

Simons-Morton, B., McLeroy, K. R., Wendel, M. L. (2012). Behavior theory in health promotion practice and research. (1st ed). Jones & Bartlett Learning, LLC

Straus, E. J. (2019). Special issue on health care transitions - Challenges in measuring healthcare transition readiness: Taking stock and looking forward. *Journal of Pediatric Nursing*, 46,

109-117. <https://doi.org/10.1016/j.pedn.2019.03.016>

Wells, F., Manning, J. (2017). Transition of care from children's to adult services. *Nursing Child*

Young People. 29(8):30-34. <https://doi.org/10.7748/ncyp.2017.e897>. PMID: 29115770.

White, P. H., Cooley, W. C., Transitions Clinical Report Authoring Group, American Academy

of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *142*(5), e20182587. <https://doi.org/10.1542/peds.2018-2587>