Healthcare Transitions for Middle Eastern Youth with Disabilities in Washington State: Access, Facilitators, Barriers, Quality of Life, and Transition Resources

Reham A. Abuatiq

A dissertation submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy in Rehabilitation Science

University of Washington
2025

Reading Committee:

Heather A. Feldner, Chair

Tracy Jirikowic

Mark Harniss

Program Authorized to Offer Degree:

Rehabilitation Medicine

University of Washington

Abstract

Healthcare Transitions for Middle Eastern Youth with Disabilities in Washington State: Access, Barriers, Quality of Life, and Resource Development

Reham A. Abuatiq

Chair of the Supervisory Committee:

Professor Heather A. Feldner

Rehabilitation Medicine

This three-article dissertation aimed to explore the experiences of Middle Eastern youth with intellectual and developmental disabilities (YIDD) during the healthcare transition (HCT) process. Despite the growing literature in HCT and unmet minority healthcare needs globally, there is limited data about the Middle Eastern YIDD experiences during this critical phase. A mixed methods approach was used to investigate the Middle Eastern YIDD and their caregivers' experiences during HCT in Washington State. The first article "Exploring an Understudied Population: Healthcare Access and Transitions of Middle Eastern Youth with Disabilities in Washington" was a qualitative study design using semi-structured interviews with 12 Middle Eastern YIDD and their caregivers. Inductive thematic analysis using NVivo software was

conducted. Four main themes emerged: Utilizing resources and support structure to access care, hurdles to care access, key concerns and priorities in navigating HCT, and key needs during HC. These highlight that despite the availability of supportive local disability resources, there are several challenges during HCT. Emphasizing the need for more culturally- sensitive approaches and comprehensive care while addressing insurance coverage is needed to improve the experiences of this population. The second article titled "Healthcare Transitioning Barriers and Facilitators from the perspectives of Middle Eastern Youth with Disabilities and their families in Washington State" investigated the HCT facilitators and barriers of this same population using photovoice narrative method with 11 participants, as one family dropped off due to availability issues. Interviews were analyzed using NVivo software and inductive thematic analysis followed by member checking. Results showed that the key HCT facilitators were healthcare providers' support; supportive healthcare facilities and clinics; independence and personal growth; and providers' cultural competence. However, health insurance coverage issues; lack of HCT planning, preparation, resources; independence and readiness to lead challenges; and gender-specific preferences were the main barriers to HCT. These highlight the need for implementing HCT best practice and guidelines to improve the HCT experiences for this sample. Further, the photovoice narrative method may be a powerful tool to empower families and communicate their needs. The final article "Health-Related Quality of Life of Middle Eastern Youth with Disabilities during Healthcare Transition in Washington State" aimed to identify and investigate how health-related quality of life (HRQOL) changes over short-term period during HCT process of this population. The current HCT literature has limited evidence about healthcare access and HRQOL of Middle Eastern YIDD during HCT. A short healthcare access survey and the World Health Quality of Life – BREF (WHOQOL-BREF) measure were collected. The WHOQOL-

BREF was collected twice, at study enrollment and after photovoice narratives interviews. Descriptive statistics and the Mann Whitney U test were conducted using R software. All participants had access to healthcare services. No statistical significance was detected between the initial and second assessments of the WHQOL-BREF raw scores. This study provided key data about healthcare access and HRQOL during HCT of this population. Future research is needed with a larger sample size to better understand Middle Eastern YIDD HRQOL levels during HCT in the United States.

This research was conducted with the approval of Human Subjects Division of the University of Washington

Applications Number & Dates of Approval:

Initial Study: STUDY00019215 January 5, 2024

Initial Study Modification: Modification ID: MOD00019147 June 27, 2024

Resources Evaluation Study: STUDY00021720 November 12, 2024

Plain Language Summary

Healthcare transfer from pediatric into adult healthcare services is a critical time in the lives of Middle Eastern Youth with intellectual and developmental Disabilities (YIDD) and their families. In Washington State, information about this population's healthcare care needs and transfer experiences is limited. There is also a lack of resources available in the Arabic language to guide this transfer.

What were the experiences of Middle Eastern YIDD and their families during healthcare transfer in Washington?

Overall, participants shared the benefits of supportive healthcare resources and structure, such as specialized doctors and clinics during care access and transfer. Participants in the study reported they were accessing healthcare services effectively. However, many participants shared challenges they had, including health insurance coverage issues and communication barriers. Their key concerns and needs during this time were maintaining care continuity and desiring more communication and information about healthcare transfer.

What makes healthcare transfer harder for Middle Eastern YIDD and families?

Specifically related to healthcare transfer, primary challenges were issues with health insurance coverage, limited care transfer planning and resources, uncertainty about youth independence and readiness to lead their healthcare interactions, and a cultural need for same-gender care providers.

What makes healthcare transfer easier for Middle Eastern YIDD?

Specific to healthcare transfer, families reported that transfer was made easier due to supportive care providers and facilities, family and clinician support for youth in working toward independence and personal growth, and provider familiarity with Middle Eastern culture.

What does the quality of life of YIDD look like during healthcare transfer?

Participants reported that youth had moderate levels of quality of life during healthcare transfer, with youth older than 21 years who had already completed transfer reporting higher quality of life compared to youth under 21 years who were still undergoing transfer.

What are the main implications of this research for Middle Eastern YIDD and their caregivers?

- It is important to maintain current supportive healthcare resources and structures such as skilled providers, clinics, and interpreters familiar with Middle Eastern culture.
- It is important to maintain currently available governmental disability support programs such as public health insurance and transportation assistance.
- Better healthcare transfer planning and preparation for YIDD is needed.
- Methods to gather data that shift the power from the researcher to the participant are an effective way for Middle Eastern YIDD and their families to share their experiences and needs.
- Future studies with a larger group of participants across the US is still needed.

Acknowledgements

This dissertation was funded by Walter C. and Anita C. Stolov Research Fund award (2023) and McEwen Family Endowed Fellowship in Physical Therapy (2023). The Gatzert Child Welfare Fellowship funded the writing phase of this dissertation during Autumn (2024).

إلى كل من غرسوا فيّ قيم الطموح والصبر إلى أبي وأمي الذين قدما لي الحب والدعم اللامحدود ين... إلى أولادي زيد؛ محمد؛ وعبد الرحمن... إلى أصدقائي ... إلى كل من وقف بجانبي وساهم في نجاحي ... أُهدي هذا البحث تقديرًا لكل لحظة دعم وكل كلمات التشجيع ... شكرًا لكم ...لكل من آمن بقدراتي على تحقيق هذا الإنجاز الكبير ... شكرا لكم من أعماق قلبي

I want to thank everyone who supported me throughout this long rewarding academic journey. To my parents and children thank you for your unlimited love and support. Thanks to my friends who constantly loved and encouraged me both here in Seattle and back in my home country Jordan.

I am deeply grateful to my mentor and role model Dr. Heather A. Feldner whose guidance was instrumental throughout this journey. To my PhD cohort, DPT students, Faculty members and staff for all of your kind smiles every day.

Thank you to all families and participants who trusted me and shared their life experiences. Thanks to the Open Doors of Multicultural Families (ODMF) staff and administration for all the support and help in recruitment.

Thanks To You All!

Table of Contents

Chapter 1. General Dissertation Introduction 15

1.1 Background 15

1.2 Overview of the Literature 17

1.3 Community Partner Organization 27

1.4 Summary of Studies 27

1.5 Flow of Dissertation 29

1.6 Bibliography 31

Chapter 2. Exploring an Understudied Population: Healthcare Access and Transitions of Middle Eastern Youth with Disabilities in Washington 39

2.1 Abstract 39

2.2 Introduction 40

2.3 Methods 42

2.4 Results 47

2.5 Discussion 59

2.6 Limitations 62

2.7 Conclusion 63

2.8 Bibliography 64

Chapter 3. Healthcare Transitioning Barriers and Facilitators from the perspectives of Middle Eastern Youth with Disabilities and their families in Washington State 69

3.1 Abstract 69

3.2 Introduction 70

3.3 Methods 72

3.4 Results 77

3.5 Discussion 99

3.6 Limitations 103

3.7 Conclusion 104

3.8 Bibliography 106

Chapter 4. Introduction 112

4.1 Part 1: Health-Related Quality of Life of Middle Eastern Youth with Disabilities during Healthcare Transition in Washington State 112

4.2 Part 2: Developing and Evaluating Healthcare Transitioning Resources for Middle Eastern Youth with Intellectual and Developmental Disabilities 131

Chapter 5. Conclusion 141

5.1 Dissertation Summary 141

5.2 Implication for research 142

Appendices: 144

Appendix A. The Healthcare Transitioning Brochure in English page 1 144

Appendix A. The Healthcare Transitioning Brochure in English page 2 146

Appendix B. The Healthcare Transitioning Brochure in Arabic page 1 147

Appendix B. The Healthcare Transitioning Brochure in Arabic page 2 148

- The English HCT Video version 149
- The Arabic HCT Video version 149

List of Figures

Figure 3.1 82

Figure 3.2 82

Figure 3.3 83

Figure 3.4 84

Figure 3.5 85

Figure 3.6 86

Figure 3.7 88

Figure 3.8 89

Figure 3.9 89

Figure 3.10 91

Figure 3.11 91

Figure 3.12 92

Figure 3.13 93

Figure 3.14 94

Figure 3.15 96

Figure 3.16 97

Figure 3.17 97

Figure 3.18 99

Figure 4.1 124

Figure 4.2 124

List of Tables

Table 2.1 The Semi-structured Interviews Questions Guide 44

Table 2.2 Demographics and Clinical Characteristics of Youth Participants 47

Table 2.3 Demographics Characteristics of Youth Caregivers 50

Table 3.1 Sample Photo Narratives Questions Guide 74

Table 3.2 Demographics and Clinical Characteristics of Youth Participants 77

Table 3.3 Demographics Characteristics of Youth Caregivers 80

Table 4.1 Demographics and Clinical Characteristics of Youth Participants 118

Table 4.2 Healthcare Access Data 121

Table 4.3 Mann-Whitney U test Results 122

Table 4.4 WHOQOL-BREF Results Over Time 122

Table 4.5 Mann Whitney U test Results of WHOQOL-BREF Based on Participants Actual Transfer 123

Table 4.6 Focus Group Discussion Questions 134

Table 4.7 Demographic Characteristics of Participants 135

Chapter 1. General Dissertation Introduction

1.1 Background

Globally, there are over 200 million children ages 5 -19 years with Intellectual and Developmental Disabilities (IDD) (Olusanya et al., 2022). In the United States (US) developmental disabilities impact more than 16% of children and adolescents (Patel et al., 2016). The term 'developmental disability' is a broad concept that covers conditions which are present at birth or start during the developmental period of one's life such as cerebral palsy, intellectual disability, autism spectrum disorder and other conditions (Patel et al., 2016). Intellectual disabilities specifically impact 2.4 % of children ages 13 – 17 years (Li et al., 2023) affecting their cognitive and adaptive behavior functions (Patel et al., 2018). While all developmental periods are significant, a critical period of development that spans from early adolescent years to young adulthood age is called youth (Hochberg & Konner, 2020). This period is characterized by evolving development in emotional and social skills (Hochberg & Konner, 2020). Despite the variability in defining an age range for this critical period, this dissertation uses the term 'youth' to refer to individuals who are 14 to 24 years old, based on the implications of this decade in life in shaping future long-term outcomes (Smith & Reeves, 2024).

During their life, Youth with Intellectual and Developmental Disabilities (YIDD) commonly experience secondary conditions that may impact their participation such as osteoporosis, epilepsy, and congenital heart defects (Liao et al., 2021). They also present with more complex health needs compared to their peers without chronic disability (Burke et al., 2019). These complex needs might impact their reported quality of life or the quality of life of other family members (Browne & Bramston, 1996). When accessing healthcare systems, YIDD face many challenges such as service availability, inaccessible services, negative attitudes, and limited knowledge about their needs (Doherty et al., 2019). All of this highlights the need for developing specialized care systems to support the needs of YIDD.

These experiences are further complicated for refugees and immigrant communities in the US who are required to navigate complex healthcare systems with limited language skills (Feinberg et al., 2020). One of these communities is Middle Eastern immigrants and refugees who face numerous contextual factors based on the intersectionality of their culture, language, and disability (Bogenschutz, 2014; Fang et al., 2015; Hoggard, 2016; Jilani, 2015; Xu et al., 2022). With approximately 3.5 million Middle Eastern immigrants living in the US (Marks et al., 2023) and limited data about the exact number of Middle Eastern YIDD due to the lack of statistical information about this cultural group (Awad et al., 2022) targeted data collection and research for this population is warranted.

Middle Eastern YIDD face a myriad of barriers ranging from complex healthcare needs and access issues to limited participation and social exclusion (Al Khatib, 2016; Alfulayyih, 2021; Al-Jumaili et al., 2020; Al-Rousan et al., 2023; Elreichouni et al., 2022; Inhorn & Serour, 2011). Further, between the ages of 14-24 YIDD undergo a critical phase of transfer out of pediatric healthcare settings to adult settings, a process called healthcare transitioning (HCT) (Betz et al., 2021). This process presents added barriers to their experiences including care coordination, communication, and insurance coverage issues (Shady et al., 2022). Compared to their typically developing peers, YIDD often experience poorer health outcomes and reduced quality of life during healthcare transition (Medforth & Boyle, 2023; Salomon & Trollor, 2018). This highlights the need for more inclusive healthcare and research strategies to address such challenges faced by this population.

1.2 Overview of the Literature

First, an introduction of two different medical and social perspectives on IDD is presented. Then, background information about Middle Eastern immigrant and refugee youth with IDD in the US is highlighted, followed by a discussion of existing literature on healthcare access, HCT, participatory action research, and health related quality of life for this population.

1.2.1 Medical and social perspectives of IDD

Medical perspective: From a medical model perspective, IDD diagnosis is an umbrella term that includes a wide range of medical conditions with limitation in physical and cognitive functions manifesting in early childhood with long term implications on social and daily living skills (Patel et al., 2018; Shree & Shukla, 2016). Intellectual disability is diagnosed based on formal intelligence testing and adaptive behavior functioning (Patel et al., 2016). Adaptive behavior refers to the individual’s ability to successfully engage in daily life responsibilities and to socially interact with others, and is considered a hallmark for achieving independence (Price et al., 2018).The intellectual function among people with intellectual disability is viewed as limited in terms of logical reasoning, problem solving, and learning skills. They also have adaptive social behavior limitations that lead to functional and participation restrictions in daily activities (Hepsiba & Raju, 2017; Jacinto et al., 2021; Tassé et al., 2016). Developmental disability is diagnosed based on physical and other functional limitations including cognitive function (Kripke, 2018; Patel et al., 2016). IDD terminology was adopted to refer to both conditions (Patel et al., 2016). Throughout the years, the diagnosis and treatment of IDD evolved toward a more inclusive care model with emphasis on biopsychosocial aspects of health and well-being (Soares de Oliveira et al., 2023). This slightly shifted the medical perspective by recognizing the role of physical, psychological, and social factors (Boyd & Baril, 2018), which facilitated a more comprehensive medical understanding of IDD. However, the medical model remains focused on the clinical characteristics and presentation when defining IDD as it seeks to quantify and qualify intellectual and functional abilities to diagnose, intervene, and treat individuals with IDD (Boat et al., 2015). This focus on “fixing” rather than addressing the societal barriers is common in the medical model and most healthcare practices with slow progression towards social and human rights approach (Groce & Kett, 2014; Healy & McKee, 2004)

Social perspective: In contrast, a social model perspective frames IDD as a socially constructed experience resulting from the interaction between the individual with IDD and the surrounding environmental barriers including physical, social, attitudinal, and communication challenges (Hogan, 2019). This view diverges from the medical perspective to a human rights perspective (Sadiki, 2024) by stressing that disability is not a problem situated within individuals with IDD, rather it is a result of the lack of accommodations and societal barriers that restrict participation and inclusion of individuals with IDD (Presnell & Keesler, 2022). This social view of disability recognizes that the individual’s medical condition exists, however, the social structure and environmental barriers are what leads to disability (Taub & Foster, 2020). By questioning predominant social norms, this perspective pushes back against practices that classify people into value added categories which result in stigma (Reber et al., 2022). This model advocates for a more inclusive society where diversity is embraced to empower individuals with disabilities and facilitate their participation in all life aspects (Feldner et al., 2022). The limitations in the social and environmental settings such as lack of accessible and inclusive designs, poor accommodations, and negative attitudes (Pope & Brandt Jr, 1997) restrain social participation and lead to further isolation and exclusion of people with IDD (Jansen-van Vuuren & Aldersey, 2020). Many people with intellectual disabilities face stigma, stereotypes, negative statements or microaggressions, inaccessibility of transportation and public spaces, and housing and employment discrimination on daily basis (Buljevac et al., 2022; Ditchman et al., 2016). Additionally, in the US, YIDD report experiencing stigma in health contexts (Hotez, 2021; Groce & Kett, 2014; Healy & McKee, 2004).

1.2.2 Middle Eastern immigrant and refugee youth with IDD

The Middle Eastern community has a distinct cultural background which impacts their views on disability (Ajami, 2016; Jansen-van Vuuren & Aldersey, 2020; Saad & Borowska-Beszta, 2019). Disability is viewed by many Middle Eastern people through a religious and cultural lens, by which many perceive it as a test of faith or a punishment from God (Saad & Borowska-Beszta, 2019; Zahra, 2017). This view commonly results in associating disability with stigma and shame, leading many families to feel obligated to hide their children with disabilities from the community, resulting in social isolation for YIDD (Saad & Borowska-Beszta, 2019). This is further deepened by the sense of guilt of having a child with disability and the limited knowledge about disability that is experienced by Arab parents (Saad & Borowska-Beszta, 2019). Further, YIDD themselves, as well as individuals who have siblings with IDD face challenges when they plan to marry. This is due to the prevalent cultural view of marriage as a union between healthy adults and concerns about disability being inherited by offspring (Saad & Borowska-Beszta, 2019). These lead to further exclusion of people with disabilities and their families, and further reinforces negative attitudes towards disability.

Additionally, there are many other cultural differences that might create misunderstandings and limits to participation in healthcare services (Hasnain et al., 2008). English language proficiency is another challenge that new immigrants and refugees in the US face (Al Shamsi et al., 2020; Goodridge, 2002). These factors create a complex environment through which YIDD and their families interact and adjust to, especially related to the US healthcare system (Mirza et al., 2014).

1.2.3 Health Care Access for Middle Eastern YIDD

Healthcare access refers to the individuals' capacity to effectively use healthcare services in order to promote health outcomes and quality of life (Andersen et al., 2007). This broad concept covers many interconnected factors that shape healthcare access experience for immigrants and refugees including care availability, affordability, navigation, and health insurance coverage (Mohammed, 2022). All these in conjunction with the specific socioeconomic status, cultural differences, and language play a crucial role in shaping one's capacity to access healthcare services (Mohammed, 2022).

Navigating the US healthcare system presents numerous challenges for YIDD especially those coming from the Middle East (Aroian et al., 2009; Goodridge, 2002; Perreira et al., 2012; Shaimaa & Bialous, 2024). While Middle Eastern YIDD may experience better living conditions compared to their home countries (Anwer, 2022), they face access barriers such as decreased English language proficiency, cultural differences, stigma, and discrimination when accessing healthcare (Aboul-Enein & Aboul-Enein, 2010; Shaimaa & Bialous, 2024). This population brings distinct cultural beliefs and values that shape their healthcare experiences, including strong family involvement in patient care, gender-specific preferences, dietary restrictions, and other religious practices such as fasting (Zagloul et al., 2024). However, research dedicated to understanding these unique cultural factors in healthcare for Arab Americans remains limited (Aboul-Enein & Aboul-Enein, 2010; Zagloul et al., 2024). .

While the Middle Eastern community grows in the US, there remains a significant gap in understanding their needs and lived experiences during healthcare access following immigration. This may lead to inadequate service delivery and care support, potentially limiting the healthcare benefits and quality of life for Middle Eastern YIDD living in the US.

1.2.4 Healthcare Transitioning (HCT)

HCT is a planned and structured process of transferring healthcare from a pediatric to an adult care setting (Berens et al., 2020). This process is usually structured and coordinated by many stakeholders including the pediatric healthcare team, youth and their caregivers, and adult care providers (Betz et al., 2021). HCT has three main phases: planning, transfer, and integration into adult care settings. The planning phase is the preparatory phase of HCT which involves patient and family education about HCT process, HCT readiness assessment, and concludes in developing HCT plan. The transfer phase forms the actual transition from pediatric care to the adult setting. It involves medical record transfer, and the transition of the patient to the new care team. Successful transfer requires receiving healthcare from professionals who do not typically treat children or young adults (Oswald et al., 2013). The integration phase is the final step, which includes making sure that the patient is enrolled in adult care with a new care plan while ensuring that they can manage their own healthcare needs. Throughout all these phases, effective coordination and communication are required to accomplish successful transfer. This process aims to enhance the ability of youth to manage their own health care and to effectively utilize the healthcare system (Berens et al., 2020). Structured HCT for youth with chronic conditions has resulted in statistically significant beneficial outcomes in terms of experience of care, parent reported quality of life, adherence to care, and population health (Gabriel et al., 2017).

In “Health care transition: The struggle to define itself", Betz et al. (2021) highlight the challenges and complexities of healthcare transition for youth with chronic health conditions. The authors describe that the HCT process is usually led by caregivers and pediatric team members (Betz et al., 2021). For YIDD, effective HCT requires careful planning, coordination, and communication between everyone in the healthcare team including the patients and their caregivers (Betz, 2023). Furthermore, during their HCT process, YIDD and their families face a fragmented healthcare system which exacerbates the challenges associated with their ongoing developmental, physical, emotional, and social needs (Betz, 2023; Betz et al., 2013, 2015). This combination of individual developmental demands and healthcare systems obstacles creates uniquely complex transition experience for YIDD and their families. To ensure a successful HCT process, healthcare systems need to implement formal HCT policies and procedures by offering HCT services, coordinating care transfer, and utilizing technology to enhance communication and information access in timely manner (Betz, 2023; Betz et al., 2015, 2016). Also, this process is often challenging since it progresses over time and varies according to the healthcare setting, service framework, and the individual’s or families’ goals (Betz et al., 2021). In addition, HCT is associated with many consequences such as loss or interruption of services, uncertainty and anxiety for youth and caregivers, and challenges with accessing resources (Gabriel et al., 2017).

HCT is a critical phase for many youths especially those with IDD (Betz, 2023; Hobart & Phan, 2019). In the US, a recent study found that YIDD have lower odds of receiving HCT services than to youth with other special needs (Casseus & Cheng, 2022). Furthermore, during HCT, immigrant families of children with IDD in the US encounter several access barriers that potentially impact their health related quality of life (HRQOL) and aggravate disparities (Xu et al., 2022). Middle Eastern YIDD and their families may find this phase uniquely challenging

(Ahmed & Ezzeddine, 2009; Björquist et al., 2017), and there is limited evidence about their experiences during their HCT phase in the US healthcare system (Minority Rights Group International, n.d.; Omran & Roudi, 1993).

Global evidence on Middle Eastern YIDD transition is also limited, with notable research including a Swedish study that investigated the challenges and needs of immigrant Middle Eastern youth with disabilities during their transition to adulthood (Björquist et al., 2017). This study found that Middle Eastern youth with disabilities rely on their parents for their care needs and leisure activities, while requiring more information about their future care and marriage (Björquist et al., 2017). Though this study provided valuable insight about Middle Eastern adulthood transitioning phase, it was conducted in a non-US context where both healthcare systems and culture may differ. Similar research studies in the US are needed to understand the specific experiences of this understudied population.

Despite the availability of descriptive and exploratory research designs in HCT for this population, an important limitation of this body of work is the limited input from the population themselves. Research on HCT for YIDD has primarily relied on descriptive analyses and exploratory designs with limited engagement of YIDD and their families in the research process (Betz et al., 2016; Brown et al., 2019; Kaehne et al., 2019). This stresses the need for utilizing more engaging and inclusive research approaches such as Participatory Action Research (PAR) which directly involves research participants in forming knowledge and understanding their transition experiences and needs.

1.2.5 Health Related Quality of Life of Middle Eastern YIDD

HRQOL is an important public health indicator that evaluates how the individual's health affects their ability to lead a fulfilling life. This health-related concept is dynamic and multidimensional in nature encompassing physical, social, psychological, and spiritual personal factors (Yin et al., 2016; Geigl et al., 2023). HRQOL is usually viewed as a subjective measure taken during a specific time frame. It accounts for both the positive and negative aspects of the person's physical, psychological, and social well-being (Geigl et al., 2023). It is a beneficial indicator of the person's overall health since it covers many individual aspects of including mental and environmental health state, as well as the impact of one's health status on quality of life. HRQOL is typically measured using several indicators that reflect how individuals perceive their health conditions and functioning (Yin et al., 2016). Several valid and reliable standardized HRQOL measures are available.

Many leading health organizations worldwide have established HRQOL as a goal for all people across the lifespan, while attracting interest from policymakers, health care providers, and researchers (Bakas et al., 2012). The application of this concept to different populations necessitates further research and careful consideration with an evident need to link HRQOL research priorities to the needs and values of patients and their families (Bakas et al., 2012). Doing this is crucial particularly for individuals with intellectual disability as several factors substantially affect their HRQOL across their life span (Ally et al., 2018; Jacinto et al., 2023). For example, particularly during their HCT process, healthcare continuity and gaps become more evident. These access limitations may further undermine HRQOL (Jacinto et al., 2023). The transition to adulthood is particularly critical for YIDD, as their mental health needs are often unmet, especially for those who have complex needs (Colizzi et al., 2020). YIDD typically experience a decline in their HRQOL during this stage mainly in the areas of autonomy, social interactions, and emotional wellbeing (Wood et al., 2018).

Assessing the quality of life of people with IDD is critical for detecting, monitoring, and reporting their needs, as well as carrying out effective and tailored individualized care and policy planning (Jacinto et al., 2023). Collecting data about HRQOL is vital for prioritizing the needs of this population and aligning care accordingly (Jacinto et al., 2023). YIDD generally report lower quality of life levels compared to their typically developing peers during their transition to adulthood (Blaskowitz et al., 2020). For Middle Eastern YIDD living in the US, this transition presents unique challenges that may impact their HRQOL due to cultural differences, language barriers, and unique healthcare needs (Abuelezam et al., 2018).

Understanding HRQOL is critical for evaluating the overall well-being of vulnerable populations such as Middle Eastern YIDD due to disability cultural stigma, unique family dynamics, privacy concerns, and intersectionality of their identities in the US society (Jansen-van Vuuren & Aldersey, 2020; Saad & Borowska-Beszta, 2019). By utilizing multiple indicators that represent individuals' perceptions of their functionality and health in relation to their physical condition and surrounding environment, researchers and healthcare providers can gain valuable insights into the specific needs and challenges faced by this population (Yin et al., 2016; Bakas et al., 2012).

1.2.6 Participatory Action Research

Participatory Action Research (PAR) is a collaborative research framework that involves active participation of stakeholders and community members in all aspects of the research process (Kindon et al., 2007; Pain et al., 2019). PAR is a continuous collaborative process that aims to enact social change and promote equity through investigating social issues using an insider perspective. This investigation is based on a cyclical process of reflection, data collection, and actions (Baum et al., 2006). PAR aims to shift the power dynamic away from the researcher to empower and engage research participants as co-researchers in identifying and solving their own problems in a specific area, with the researcher acting as a collaborator and facilitator with the community rather than an outsider conducting research on a community (Asaba & Suarez-Balcazar, 2018; Cahill, 2007; Grant et al., 2008). PAR also fosters conscious and action-oriented results that can facilitate social change for marginalized community (Brydon-Miller, 1997). PAR enables the emphasis on action to improve the area of interest and gain the desired change.

Related to disability research specifically, PAR facilitates understanding disability from an insider's perspective which may lead to detecting new strengths (Balcazar et al., 2006). Further, PAR has the potential to address research power imbalances by empowering research participants and fostering a disability responsive approach (Muller et al., 2015).

This framework forms a valuable tool to address the challenges faced by Middle Eastern YIDD and to identify strengths and promote a sense of trust and problem ownership among research participants by actively involving them in the research process (Grant et al., 2008). This framework could potentially facilitate social change and help in co-creating HCT resources that meets the needs of this population (Pain et al., 2019). In conclusion, PAR forms a promising research framework to bridge the tensions between researchers and communities. This dissertation employed one PAR method to actively involve Middle Eastern YIDD and their caregivers in the HCT knowledge creation aiming to provide meaningful and culturally responsive services.

1.3 Community Partner Organization

This dissertation was conducted in partnership with a community organization. Open Doors for Multicultural Families (ODMF) is a local non-profit organization that is located in Washington State. It provides diverse cultural and linguistical services and programs for families and individuals with intellectual and developmental disabilities. This organization primarily serves immigrants, refugees, and people of color, providing culturally responsive services in multiple languages, including Arabic, to over than 2,000 families. ODMF collaborated with the researcher (Abuatiq) through recruitment facilitation and building connections with the Middle Eastern community. They also provided support and advice throughout the research process and facilitated planning and delivery of a community engaged photo exhibit that resulted from one of the dissertation studies.

1.4 Summary of Studies

This dissertation aimed to investigate the experiences of Middle Eastern YIDD and their families using mixed methods while incorporating one participatory action research method, photovoice narratives. Prior research on HCT for individuals with IDD was restricted to exploratory methodologies (Kaehne et al., 2019) and very limited research has been conducted with Middle Eastern immigrants and refugees, specifically (Björquist et al., 2017).

The first study titled “Exploring an Understudied Population: Healthcare Access and Transitions of Middle Eastern Youth with Disabilities in Washington” aimed to explore the experiences of Middle Eastern YIDD and their caregivers during healthcare access and HCT in Washington State using qualitative semi-structured interviews. Twelve Middle Eastern youth (ages 14-24 years) and their primary caregivers participated between March and October 2024. An inductive thematic analysis using NVivo qualitative analysis software, complemented by member checking, was employed to identify the key themes. The resulting themes were: 1) Utilizing resources and support structure to access care, 2) Hurdles to care access, 3) Key concerns and priorities in navigating HCT, and 4) Key needs during HCT.

The second study titled “Healthcare Transitioning Barriers and Facilitators from the perspectives of Middle Eastern Youth with Disabilities and their families in Washington State” aimed to explore current HCT facilitators and barriers from the perspectives of Middle Eastern YIDD in Washington State. Photovoice narrative method was utilized using cell phone cameras and a list of guiding questions with eleven of the same Middle Eastern YIDD and their families that took part in the first study. Interviews were analyzed using NVivo qualitative analysis software, inductive thematic analysis, and member checking. The emerging themes as key HCT facilitators were: Healthcare providers’ support, supportive healthcare facilities and clinics, independence and personal growth, and providers’ cultural competence. Themes emerging related to HCT barriers included: Health insurance coverage issues, lack of HCT planning, preparation, resources, independence and readiness to lead; and gender-specific preferences.

The third study titled “Health-Related Quality of Life of Middle Eastern Youth with Disabilities during Healthcare Transition in Washington State” utilized quantitative methodology to examine responses on the World Health Quality of Life – BREF (WHOQOL-BREF) measure and a short healthcare access survey that were collected from the same 11 Middle Eastern youth with intellectual and developmental disabilities (ages 14-24) and their caregivers in the previous study. The WHOQOL-BREF was collected twice throughout an overarching study that took place over a 2–3 month period. Results revealed that all participants had access to healthcare services, while generally having lower HRQOL scores across physical health, psychological health, and environment domains compared to the normative data for this population. Mann –

Whitney U tests for the transformed scores of the WHOQOL-BREF resulted in no statistically significant changes in reported HRQOL over the course of the study. Interestingly, participants who recently transferred into adult services exhibited higher mean changes in the physical, psychological, and environmental health domains than those who did not yet transfer. This suggests that Middle Eastern YIDD in this study may face significant challenges in physical health, psychological well-being, and environmental conditions during their transition to adult health services.

In addition to this third study, and based on the results obtained from all studies described above, the final step in the dissertation was to develop and conduct initial peer evaluations on two novel HCT resources, created in English and Arabic, to help guide the HCT process for Middle Eastern YIDD and their families. The evaluation of the preliminary resources took place during a focus group that consisted of families that participated in the above studies as well as key informants from community partner ODMF. The results of the focus group were compiled into themes and will be used to revise and refine the developed resources prior to sharing them among the Middle Eastern families served by ODMF and other similar organizations.

1.5 Flow of Dissertation

This dissertation includes three linked papers and two preliminary HCT resources that were developed and evaluated based on the results of earlier study activities. A brief introduction and overview of this dissertation is presented in chapter one. Chapters two, three, and four include the three complete articles that are planned for submission to peer-reviewed journals. Each article contains an abstract, introduction, methods, results, discussion, conclusion, and references. Chapter four also includes the two HCT resources: a brochure and a video in Arabic and English. These resources were preliminary evaluated by a focus group of Middle Eastern caregivers. Chapter five concludes and summarizes this dissertation's findings and provides future research recommendations and directions.

1.6 Bibliography

Aboul-Enein, B. H., & Aboul-Enein, F. H. (2010). The cultural gap delivering health care services to Arab American populations in the United States. *Journal of Cultural Diversity*, *17*(1).

Ahmed, S., & Ezzeddine, M. (2009). Challenges and opportunities facing American Muslim youth. *Journal of Muslim Mental Health*, *4*(2), 159–174.

Ajami, H. (2016). Arabic language, culture, and communication. *International Journal of Linguistics and Communication*, *4*(1), 120–123.

Al Khatib, J. M. (2016). *Arab American children with disabilities: Considerations for teachers and service providers*. Routledge.

Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). Implications of language barriers for healthcare: a systematic review. *Oman Medical Journal*, *35*(2), e122.

Alfulayyih, M. (2021). *Rehabilitation Counseling Perceptions and Psychosocial Stressors of Arab-immigrant Caregivers of Children with Autism Spectrum Disorder*.

Al-Jumaili, A. A., Ahmed, K. K., & Koch, D. (2020). Barriers to healthcare access for Arabic-speaking population in an English-speaking country. *Pharmacy Practice (Granada)*, *18*(2).

Ally, S., Boyd, K., Abells, D., Amaria, K., Hamdani, Y., Loh, A., Niel, U., Sacks, S., Shea, S., & Sullivan, W. F. (2018). Improving transition to adulthood for adolescents with intellectual and developmental disabilities: Proactive developmental and systems perspective. *Canadian Family Physician*, *64*(Suppl 2), S37–S43.

Al-Rousan, T., Kamalyan, L., Bernstein Sideman, A., Miller, B., AlHeresh, R., Moore, A., Marquine, M. J., Argeros, G., & Ajrouch, K. J. (2023). Migration and Cognitive Health Disparities: The Arab American and Refugee Case. *The Journals of Gerontology: Series B*, *78*(1), 111–123. https://doi.org/10.1093/geronb/gbac129

Andersen, R. M., Davidson, P. L., & Baumeister, S. E. (2007). Improving access to care in America. *Changing the US Health Care System: Key Issues in Health Services Policy and Management. 3a. Edición. San Francisco: Jossey-Bass*, 3–31.

Anwer, A. (2022). THE AMERICAN DREAM AND MUSLIM AMERICANS. *The Routledge Handbook on the American Dream: Volume 2*.

Aroian, K., Hough, E. S., Templin, T. N., Kulwicki, A., Ramaswamy, V., & Katz, A. (2009). A model of mother–child adjustment in Arab Muslim immigrants to the US. *Social Science & Medicine*, *69*(9), 1377–1386.

Asaba, E., & Suarez-Balcazar, Y. (2018). Participatory research: A promising approach to promote meaningful engagement. In *Scandinavian Journal of Occupational Therapy* (Vol. 25, Issue 5, pp. 309–312). Taylor & Francis.

Awad, G. H., Abuelezam, N. N., Ajrouch, K. J., & Stiffler, M. J. (2022). Lack of Arab or Middle Eastern and North African health data undermines assessment of health disparities. *American Journal of Public Health*, *112*(2), 209–212.

Bakas, T., McLennon, S. M., Carpenter, J. S., Buelow, J. M., Otte, J. L., Hanna, K. M., Ellett, M. L., Hadler, K. A., & Welch, J. L. (2012). Systematic review of health-related quality of life models. *Health and Quality of Life Outcomes*, *10*(1), 134. https://doi.org/10.1186/1477-7525-10-134

Balcazar, F., Keys, C., & Kaplan, D. (2006). Participatory Action Research and People with Disabilities: Principles and Challenges. *Canadian Journal of Rehabilitation*, *12*.

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, *60*(10), 854.

Berens, J., Wozow, C., & Peacock, C. (2020). Transition to adult care. *Physical Medicine and Rehabilitation Clinics*, *31*(1), 159–170.

Betz, C. L. (2023). Health care transition planning for adolescents and emerging adults with intellectual disabilities and developmental disabilities: Distinctions and challenges. *Journal for Specialists in Pediatric Nursing*, *28*(3), e12415.

Betz, C. L., Coyne, I., & Hudson, S. M. (2021). Health care transition: The struggle to define itself. *Comprehensive Child and Adolescent Nursing*, 1–15.

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook*, *61*(5), 311–336.

Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *Journal of Family Nursing*, *21*(3), 362–412.

Betz, C. L., O'Kane, L. S., Nehring, W. M., & Lobo, M. L. (2016). Systematic review: Health care transition practice service models. *Nursing Outlook*, *64*(3), 229–243.

Björquist, E., Nordmark, E. A. K., Almasri, N. A., & Kristensson Hallström, I. (2017). Immigrant Youths with Disabilities and Caregivers from the Middle-East—Challenges and Needs During Transition to Adulthood. *Research in Health Science*, *2*(4), 363–384.

Boat, T. F., Wu, J. T., & National Academies of Sciences and Medicine, E. (2015). Clinical characteristics of intellectual disabilities. In *Mental disorders and disabilities among low-income children*. National Academies Press (US).

Bogenschutz, M. (2014). "We find a way": challenges and facilitators for health care access among immigrants and refugees with intellectual and developmental disabilities. *Medical Care*, *52*, S64–S70.

Boyd, K., & Baril, V. (2018). Aging with Intellectual and Developmental Disabilities. *Geriatric Psychiatry: A Case-Based Textbook*, 577–594.

Browne, G., & Bramston, P. (1996). Quality of life in the families of young people with intellectual disabilities. *The Australian and New Zealand Journal of Mental Health Nursing*, *5*(3), 120–130.

Brydon-Miller, M. (1997). Participatory action research: Psychology and social change. *Journal of Social Issues*, *53*(4), 657–666.

Buljevac, M., Milić Babić, M., & Leutar, Z. (2022). 'You don't have to tell me in person i'm not to your liking': experiences of discrimination of people with intellectual disabilities. *International Journal of Disability, Development and Education*, *69*(3), 837–852.

Burke, É., O'Dwyer, M., McGlinchey, E., Foran, S., Phadraig, C. M., Carroll, R., McCallion, P., & McCarron, M. (2019). Overview of the Important Physical Health Concerns. *Physical Health of Adults with Intellectual and Developmental Disabilities*, 27–52.

Cahill, C. (2007). Doing research with young people: Participatory research and the rituals of collective work. *Children's Geographies*, *5*(3), 297–312.

Casseus, M., & Cheng, J. (2022). Variations in healthcare transition preparation among youth with chronic conditions. *American Journal of Preventive Medicine*, *62*(5), e275–e283.

Colizzi, M., Lasalvia, A., & Ruggeri, M. (2020). Prevention and early intervention in youth mental health: is it time for a multidisciplinary and trans-diagnostic model for care? *International Journal of Mental Health Systems*, *14*(1), 1–14.

Ditchman, N., Kosyluk, K., Lee, E.-J., & Jones, N. (2016). How stigma affects the lives of people with intellectual disabilities: An overview. *Intellectual Disability and Stigma: Stepping out from the Margins*, 31–47.

Doherty, A. J., Atherton, H., Boland, P., Hastings, R. P., Hives, L., Hood, K., James-Jenkinson, L., LEAVEY, R., Randell, L., & Reed, J. (2019). *Barriers and facilitators to primary health care for physical and or mental health issues experienced by adolescents and adults with intellectual disabilities (only), autism (only), or both: an integrative review*.

Elreichouni, A., Aly, S., Maciejewski, K., Salem, I., Ghossein, N., Mankash, M. S., Dziura, J., & Mowafi, H. (2022). Health services access, utilization, and barriers for Arabic-speaking refugees resettled in Connecticut, USA. *BMC Health Services Research*, *22*(1), 1–9.

Fang, M. L., Sixsmith, J., Lawthom, R., Mountian, I., & Shahrin, A. (2015). Experiencing 'pathologized presence and normalized absence'; understanding health related experiences and access to health care among Iraqi and Somali asylum seekers, refugees and persons without legal status. *BMC Public Health*, *15*(1), 1–12.

Feldner, H. A., Evans, H. D., Chamblin, K., Ellis, L. M., Harniss, M. K., Lee, D., & Woiak, J. (2022). Infusing disability equity within rehabilitation education and practice: A qualitative study of lived experiences of ableism, allyship, and healthcare partnership. *Frontiers in Rehabilitation Sciences*, *3*. https://doi.org/10.3389/fresc.2022.947592

Gabriel, P., McManus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: a systematic review. *The Journal of Pediatrics*, *188*, 263–269.

Geigl, C., Loss, J., Leitzmann, M., & Janssen, C. (2023). Social factors of health-related quality of life in older adults: a multivariable analysis. *Quality of Life Research*, *32*(11), 3257–3268.

Goodridge, E. (2002). Meeting the health needs of refugees and immigrants: Language and cultural barriers contribute to the challenge of caring for refugees, who bring to the United States health risks, needs, and diseases that may be unfamiliar.(Cover Article). *JAAPA-Journal of the American Academy of Physicians Assistants*, *15*(1), 20–27.

Grant, J., Nelson, G., & Mitchell, T. (2008). Negotiating the challenges of participatory action research: Relationships, power, participation, change and credibility. *Handbook of Action Research*, 589–607.

Groce, N., & Kett, M. (2014). Youth with Disabilities. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.3385379

Hasnain, R., Shaikh, L. C., & Shanawani, H. (2008). *Disability and the Muslim perspective: An introduction for rehabilitation and health care providers*.

Healy, J., & McKee, M. (2004). Meeting the needs of people with disabilities. In *Accessing Healthcare* (pp. 55–70). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198516187.003.0004

Hepsiba, H., & Raju, M. V. R. (2017). Intellectual Disability. *International Research Journal of Engineering, IT and Scientific Research*, *3*(5), 34–43.

Hobart, C. B., & Phan, H. (2019). Pediatric-to-adult healthcare transitions: current challenges and recommended practices. *American Journal of Health-System Pharmacy*, *76*(19), 1544–1554.

Hochberg, Z. ev, & Konner, M. (2020). Emerging adulthood, a pre-adult life-history stage. *Frontiers in Endocrinology*, *10*, 918.

Hogan, A. J. (2019). Social and medical models of disability and mental health: evolution and renewal. *CMAJ*, *191*(1), E16–E18.

Hoggard, M. T. (2016). *Barriers to Health Care Access for Refugees in Cache County, Utah*.

Hotez, E. (2021). One of Us: Combating Stigma Against People with Intellectual and Developmental Disabilities. *APS Observer*, *34*.

Inhorn, M. C., & Serour, G. I. (2011). Islam, medicine, and Arab-Muslim refugee health in America after 9/11. *The Lancet*, *378*(9794), 935–943.

Jacinto, M., Rodrigues, F., Monteiro, D., Antunes, R., Ferreira, J. P., Matos, R., & Campos, M. J. (2023a). Quality of Life in Individuals with Intellectual and Developmental Disabilities: The Congruency Effect between Reports. *Healthcare*, *11*(12), 1748.

Jacinto, M., Vitorino, A. S., Palmeira, D., Antunes, R., Matos, R., Ferreira, J. P., & Bento, T. (2021). Perceived barriers of physical activity participation in individuals with intellectual disability—A systematic review. *Healthcare*, *9*(11), 1521.

Jansen-van Vuuren, J., & Aldersey, H. M. (2020). Stigma, acceptance and belonging for people with IDD across cultures. *Current Developmental Disorders Reports*, *7*, 163–172.

Jilani, I. J.-S. (2015). *Muslim American identity under siege: Muslim students' perspective of American high schools*. Northeastern University.

Kaehne, A., Kiernan, J., & Ridley, J. (2019). Systematic review of study designs and methods in health transition research for young people with intellectual disabilities. *Heliyon*, *5*(11), e02750.

Kindon, S., Pain, R., & Kesby, M. (2007). Participatory action research: Origins, approaches and methods. In *Participatory action research approaches and methods* (pp. 35–44). Routledge.

Kripke, C. (2018). Adults with developmental disabilities: a comprehensive approach to medical care. *American Family Physician*, *97*(10), 649–656.

Li, Q., Li, Y., Zheng, J., Yan, X., Huang, J., Xu, Y., Zeng, X., Shen, T., Xing, X., & Chen, Q. (2023). Prevalence and trends of developmental disabilities among US children and adolescents aged 3 to 17 years, 2018–2021. *Scientific Reports*, *13*(1), 17254.

Liao, P., Vajdic, C., Trollor, J., & Reppermund, S. (2021). Prevalence and incidence of physical health conditions in people with intellectual disability–a systematic review. *PloS One*, *16*(8), e0256294.

Marks, R., Jacobs, P., & Coritz, A. (2023). Lebanese, Iranian and Egyptian populations represented nearly half of the MENA population in 2020 Census. *US Census Bureau*.

Minority Rights Group International. (n.d.). *Arab and other Middle Eastern Americans*. Retrieved May 9, 2023, from https://minorityrights.org/minorities/arab-and-other-middle-eastern-americans/

Mirza, M., Luna, R., Mathews, B., Hasnain, R., Hebert, E., Niebauer, A., & Mishra, U. D. (2014). Barriers to healthcare access among refugees with disabilities and chronic health conditions resettled in the US Midwest. *Journal of Immigrant and Minority Health*, *16*, 733–742.

Mohammed, M. (2022). *Barriers to Healthcare Access for Refugees and Immigrants with Limited English Proficiency in Nebraska: A Systematic Review of the Literature*.

Muller, J., Ned, L., & Duvenage, M. (2015). A Coordinated Collaborative Response to Rehabilitation Needs of Persons with Disabilities. *Archives of Physical Medicine and Rehabilitation*, *2*, 1056.

Olusanya, B. O., Kancherla, V., Shaheen, A., Ogbo, F. A., & Davis, A. C. (2022). Global and regional prevalence of disabilities among children and adolescents: analysis of findings from global health databases. *Frontiers in Public Health*, *10*, 977453.

Omran, A. R., & Roudi, F. (1993). The middle east population puzzle. *Population Bulletin*, *48*(1), 1–40.

Oswald, D. P., Gilles, D. L., Cannady, M. S., Wenzel, D. B., Willis, J. H., & Bodurtha, J. N. (2013). Youth with special health care needs: transition to adult health care services. *Maternal and Child Health Journal*, *17*(10), 1744–1752.

Pain, R., Whitman, G., & Milledge, D. (2019). *Participatory action research toolkit: An introduction to using PAR as an approach to learning, research and action*.

Patel, D. R., Apple, R., Kanungo, S., & Akkal, A. (2018). Narrative review of intellectual disability: definitions, evaluation and principles of treatment. *Pediatric Medicine*, *1*.

Patel, D. R., Greydanus, D. E., Merrick, J., & Rubin, I. L. (2016). Introduction to intellectual and developmental disabilities. *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, 5–12.

Perreira, K. M., Crosnoe, R., Fortuny, K., Pedroza, J., Ulvestad, K., Weiland, C., Yoshikawa, H., & Chaudry, A. (2012). Barriers to immigrants' access to health and human services programs. *ASPE Issue Brief. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation*.

Pope, A. M., & Brandt Jr, E. N. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering*.

Presnell, J., & Keesler, J. (2022). Community Inclusion for People with Intellectual and Developmental Disabilities. *Advances in Social Work*, *21*(4), 1229–1245. https://doi.org/10.18060/25512

Price, J. A., Morris, Z. A., & Costello, S. (2018). The application of adaptive behaviour models: a systematic review. *Behavioral Sciences*, *8*(1), 11.

Reber, L., Kreschmer, J. M., James, T. G., Junior, J. D., DeShong, G. L., Parker, S., & Meade, M. A. (2022). Ableism and contours of the attitudinal environment as identified by adults with long-term physical disabilities: a qualitative study. *International Journal of Environmental Research and Public Health*, *19*(12), 7469.

Saad, M. A. E., & Borowska-Beszta, B. (2019). Disability in the Arab world: a comparative analysis within culture. *Psycho-Educational Research Reviews*, *8*(2), 29–47.

Sadiki, M. C. (2024). *Promoting Social Inclusion and Support of People With Intellectual and Developmental Disabilities* (pp. 389–412). https://doi.org/10.4018/979-8-3693-3176-7.ch017

Shady, K., Phillips, S., & Newman, S. (2022). Barriers and facilitators to healthcare access in adults with intellectual and developmental disorders and communication difficulties: an integrative review. *Review Journal of Autism and Developmental Disorders*, 1–13.

Shaimaa, E., & Bialous, S. (2024). Mental Health Care Access Among Arab Immigrants in the United States: Application of Public Arena Model. *Community Mental Health Journal*, *60*(2), 376–384.

Shree, A., & Shukla, P. C. (2016). Intellectual Disability: Definition, classification, causes and characteristics. *Learning Community-An International Journal of Educational and Social Development*, *7*(1), 9.

Smith, E., & Reeves, R. V. (2024). *The decisive decade: Understanding the trajectories of 14-to 24-year-olds*.

Soares de Oliveira, F. E., Nobre de Oliveira, A. G., & Soares de Oliveira, L. K. (2023). Recent Advances in the Understanding and Intervention of Intellectual and Developmental Disabilities: A Mini Review. *Global Journal of Intellectual & Developmental Disabilities*, *12*(2). https://doi.org/10.19080/GJIDD.2023.12.555832

Tassé, M. J., Luckasson, R., & Schalock, R. L. (2016). The relation between intellectual functioning and adaptive behavior in the diagnosis of intellectual disability. *Intellectual and Developmental Disabilities*, *54*(6), 381–390.

Taub, D., & Foster, M. (2020). Inclusion and intellectual disabilities: A cross cultural review of descriptions. *International Electronic Journal of Elementary Education*, *12*(3), 275–281.

Wood, D., Crapnell, T., Lau, L., Bennett, A., Lotstein, D., Ferris, M., & Kuo, A. (2018). Emerging adulthood as a critical stage in the life course. *Handbook of Life Course Health Development*, 123–143.

Xu, Y., Zeng, W., Wang, Y., & Magana, S. (2022). Barriers to service access for immigrant families of children with developmental disabilities: A scoping review. *Intellectual and Developmental Disabilities*, *60*(5), 382–404.

Yin, S., Njai, R., Barker, L., Siegel, P. Z., & Liao, Y. (2016). Summarizing health-related quality of life (HRQOL): development and testing of a one-factor model. *Population Health Metrics*, *14*(1), 22. https://doi.org/10.1186/s12963-016-0091-3

Zagloul, M., Mohammed, B., Abufares, N., Sandozi, A., Farhan, S., Anwer, S., Tumusiime, S., & Bojang, M. (2024). Review of Muslim Patient Needs and Its Implications on Healthcare Delivery. *Journal of Primary Care & Community Health*, *15*, 21501319241228740.

Zahra, S. A. Ben. (2017). *Arab Islamic Voices, Agencies, and Abilities: Disability Portrayals in Muslim World Literature and Culture*. Lexington Books.

Chapter 2. Exploring an Understudied Population: Healthcare Access and Transitions of Middle Eastern Youth with Disabilities in Washington

2.1 Abstract

Introduction: This study explored the experiences of Middle Eastern youth with intellectual and developmental disabilities (YIDD) while accessing healthcare systems in the Washington States and during their healthcare transitioning (HCT) into adult services. **Methods:** Qualitative Semi-structured interviews were conducted with twelve Middle Eastern youth (ages 14-24 years) and their primary caregivers between March and October 2024. An inductive thematic analysis using NVivo software, complemented by member checking, was employed to identify the key themes. **Results:** The analysis resulted in four main themes: Utilizing resources and support structure to access care, hurdles to care access, key concerns and priorities in navigating HCT, and key needs during HC. **Conclusion and Discussion:** These findings reveal the value of the local disability supportive resources and structures while identifying several challenges experienced by Middle Eastern YIDD and their caregivers. This suggests that developing culturally sensitive care, implementing HCT best practices and guidelines, while addressing access challenges is needed to improve the experiences of this community. These findings can inform policy makers and healthcare providers to better serve this population. Recommendations include providing comprehensive insurance coverage, communication solutions, specialized care needs, and recreational activities for Middle Eastern YIDD. Further research is needed with larger sample and across the United States to better serve this population.

2.2 Introduction

The intersectionality between disability, culture, and nationality poses complex challenges for many people with disabilities. The United States (US) hosts around 3.5 million Middle Eastern immigrants (Marks et al., 2023), with an estimated 5-10% of Arab Americans having functional disabilities (Read et al., 2019). This population has distinct cultural beliefs and values that shape their healthcare experience such as strong family involvement in patient care, gender specific preferences, dietary restrictions, and religious practice (Zagloul et al., 2024). Despite this, there is limited healthcare research dedicated to understanding these unique cultural beliefs and practices of Arab Americans (Aboul-Enein & Aboul-Enein, 2010; Zagloul et al., 2024). As this population grows in the US, it is crucial to understand their healthcare experiences with regard to healthcare access and transition for Middle Eastern youth with intellectual and developmental disabilities (YIDD).

As YIDD transition into adulthood, they face a complex healthcare system that may not be fully prepared to meet their needs in light of their unique cultural background (Björquist et al., 2017; Brown et al., 2019). Further, there is a need for culturally tailored interventions and transition programs to meet the needs of the diverse population in the US (Betz, 2023; Joo & Liu, 2021). This is further complicated by the fact that the US healthcare systems are different from their home countries' systems. The US has healthcare systems have a wider range of specialized services with advanced medical technologies (Blumenthal et al., 2024; Squires & Anderson, 2015), while Middle Eastern systems have different approaches to service delivery, insurance coverage, and quality compared to the US (Asbu et al., 2017; Mate et al., 2017). This difference is particularly evident in the services provided for YIDD, as the US offers a more comprehensive support systems with specialized care options for this population (Gréaux et al., 2023). The Middle Eastern healthcare systems face challenges in providing similar measures due to shortages of qualified staff and limited resources such as medication and/or therapies (Katoue et al., 2022). However, it is crucial to recognize that immigrants and refugees in the US often encounter challenges when accessing healthcare systems leading to disparities in healthcare (Kuehn, 2021; Lebrón et al., 2023; Wilson & Stimpson, 2020). For instance, public health insurances and federally funded programs requires lawful immigration status for qualification such as Medicare and Medicaid (Alarcon, 2022).

Healthcare access is defined as the capacity to effectively use health services in order to promote one's health outcomes (Andersen et al., 2007; Simaroj et al., 2023). Middle Eastern YIDD in the US are reported to have better living conditions compared to the same population in their home countries (Anwer, 2022). However, they face distinct challenges when accessing the US healthcare system that may be exacerbated by English language barriers, cultural differences, stigma, and discrimination (Aboul-Enein & Aboul-Enein, 2010; Shaimaa & Bialous, 2024). Some of the reported barriers for immigrants and refugees with intellectual disabilities in the US include difficulties in finding accurate information on insurance and providers, issues with coordinating multiple specialty appointments, and lack of cultural competence (Bogenschutz, 2014). For refugees with disabilities and chronic conditions, healthcare access barriers included inadequate coverage of health insurance, language and communication barriers, and the complex structure of the US healthcare systems (Mirza et al., 2014).

Additionally, the healthcare transitioning (HCT) process, which involves transferring from pediatric care to adult care services (Betz et al., 2021), is a crucial period in the lifespan of YIDD that can significantly impact their long-term health outcomes and quality of life (Mahan et al., 2017). Globally, evidence on Middle Eastern YIDD transition is limited. Notable research includes a Swedish study investigated the challenges and needs of immigrant Middle Eastern youth with disabilities during their transition to adulthood. This study found that adulthood transition might be complicated by Middle Eastern specific factors such as different cultural expectations, independence, and potential patient-provider misunderstandings due to language and cultural differences (Björquist et al., 2017).

Despite the importance of access to healthcare, especially during this transition period in the lives of YIDD, there is limited research in the US focusing on the interconnected constructs of healthcare access and the experiences of this population during HCT. This knowledge gap may lead to inadequate service delivery and support for Middle Eastern YIDD, potentially limiting their healthcare benefits and quality of life as immigrants and refugees in the US.

Addressing this gap, this study aims to investigate the experiences of Middle Eastern YIDD with healthcare access and HCT in Washington State. Various initiatives were implemented in Washington to improve healthcare access of immigrants such as Medicaid coverage expansion and establishing the Apple Health Expansion program for undocumented immigrants (Washington State Hospital Association, 2024; Yen, 2010). However, there is limited evidence on how these programs impact the Middle Eastern YIDD. Hence, this study aims to understand the experiences of Middle Eastern YIDD and their families during this vital time to guide future research and inform healthcare service delivery for this vulnerable population.

2.3 Methods

All study procedures were conducted with ethics approval from the University of Washington Human Subjects Division (IRB ID # STUDY00019215). Informed consent and assent along with parental permission was secured from all participants before study enrollment.

2.3.1 Positionality Statement

As a Middle Eastern mother, experienced physical therapist, and a recent immigrant to the US, I share cultural, linguistic, and religious background with the study participants. This positionality facilitated rapport-building and helped overcome potential barriers during the research process. However, I acknowledge that my status as a non-disabled researcher and have no children with disabilities may limit my full understanding of the participants' and their caregivers' lived experiences. To address this limitation, I maintained a reflexivity journal and I consulted my peers and mentor to identify and mitigate potential biases. To ensure the accuracy of my interpretations, member checking was implemented. While recognizing that my intersectionality with this population both in background and language had inevitably influenced my research perspective, I was committed to ethical practice and centering their perspective throughout this study. For a detailed positionality statement see appendix D.

2.3.2 Study Design

This qualitative study employed semi-structured interviews to gain an in-depth understanding of the unique experiences of Middle Eastern YIDD. This design is valuable when knowledge about a specific population is limited (Creswell & Poth, 2016) as it provides flexible, yet focused data collection method (Gibson et al., 2013; Merriam & Tisdell, 2015). Semi-structured interviews facilitate discussions about the main research topics while allowing participants the freedom to elaborate on any additional points (Merriam & Tisdell, 2015). This approach is advantageous to capture nuanced experiences of Middle Eastern YIDD and their caregivers.

To establish shared understanding of healthcare access and HCT, both concepts were explained and defined in lay language (either Arabic or English) to all participants at the beginning of all interviews to ensure clarity and consistency.

2.3.3 Data Collection Method:

Semi-structured interviews were conducted in a linguistic flexible format by offering either Arabic or English languages options to ensure participants comfort and to fully express themselves using their language of choice for communication (Svensson, 2024). The researcher, one caregiver, and YIDD participated in a one-hour audio recorded interview. These interviews were then transcribed verbatim both in English and Arabic. The researcher translated the Arabic interviews into English, as the researcher is a native Arabic language speaker.

Table 2.1 presents the semi-structured interview guide. Different retention strategies were used such as flexible interview times, dates, and format including in-person and virtual.

Table 2.1 The Semi-structured Interview Questions Guide

1. What are your future goals?
2. What does health and wellness mean for you and your family?
3. Describe how you currently access healthcare services for yourself/your child?
4. While navigating the local healthcare system, which resources supported you?
5. What challenges you faced when accessing local healthcare systems?
6. Have you managed to overcome these challenges? If yes, how did you overcome them?

7. Has your family talked about how to handle your health needs in the future when you become an adult? If so, how?
8. Have any of your/your child's healthcare discussions included plans for healthcare transition from pediatric to adult services?
9. What are your biggest concerns or priorities in your/your child's healthcare transition? How do you plan to address these concerns or priorities?
10. What advice would you give to another family going through this same experience?

2.3.4 Participants

Participants were recruited in collaboration with Open Doors for Multicultural Families (ODMF), which is a local non-profit community organization that supports diverse families and children with disabilities. Additionally, study flyers were distributed using emails, social media platforms (WhatsApp, Facebook, and Instagram), and two local community centers in Washington State. The inclusion criteria for youth participants were: Middle Eastern immigrants or refugees living in Washington State, aged 14-24 years, any gender, diagnosed with intellectual or developmental disability. The caregivers' inclusion criteria were: aged 18 years or older, legal guardian of Middle Eastern YIDD, primary caregiver of the Middel Eastern YIDD, and living in the same household with the Middle Eastern YIDD. For both the youth and caregiver participants, their common inclusion criteria included their ability and willingness to participate in a one-hour research interview either in-person or on zoom and be able to communicate in either Arabic or English language.

Recruitment was facilitated through working with a trusted local community organization (ODMF) which facilitated connections and trust building with the Middle Eastern community. Confidentiality and privacy were explained and stressed to participants, while informing families about the research aims, goals, and potential benefits.

2.3.5 Data analysis

Data analysis of the interview transcripts was conducted using an inductive thematic analysis method (Braun & Clarke, 2006; Elo & Kyngäs, 2008; Peel, 2020) which consisted of independent analysis by the researcher using open and focused coding until themes emerged. Data saturation was reached after iterative analysis of the interviews till no new themes emerged (Ando et al., 2014). The emerging unique perspectives were addressed through member checking and themes refinement (Vasileiou et al., 2018).

NVivo software was used to organize and assist with thematic analysis (Massachusetts, 2023). Initial emerging themes were discussed across multiple meetings with a research mentor that was not involved in data collection to refine themes and ensure consistency of interpretation (Nowell et al., 2017). Once the initial themes reached consensus, they were translated back into Arabic and shared with participants as a form of member checking (Nowell et al., 2017). This included a streamlined process to enhance the credibility and trustworthiness of the findings (Birt et al., 2016). This process involved preparing a concise summary of the main emerging themes and supporting aggregate data which was shared with all participants via email for review. Then a brief follow-up phone call of 15 minutes was conducted with each participant during which focused validation questions were asked: 1) Do these themes accurately reflect your experiences? and 2) Is there anything important missing or that should be changed? Notes were taken during each call and immediate review of the themes was done after the call to ensure comprehensive documentation of participants' feedback. The participants' feedback was analyzed for consistencies and concerns about the preliminary themes. Based on this analysis, themes were refined incorporating valid participants' feedback. This ensured that the resulting themes were aligned with the participants' lived experiences. This validation process ensured that participants had an opportunity to confirm or clarify themes enhancing the credibility of this analysis (Tracy, 2010).

2.4 Results

2.4.1 Demographic Data

A total of 12 Middle Eastern youth and families participated in this study. Tables 2.2 and 2.3 show their demographic data. Only 3 YIDD were actively involved in these interviews. 12 families reported that their child attends one or more specialty clinics.

Table 2.2 Demographics and Clinical Characteristics of Youth Participants

Characteristic	**N**
Age, years	
Mean (SD)	18.3 (3.2)
Range	14 – 24
Gender	
Male	7
Female	5
Medical Diagnosis	
Cerebral Palsy	4
Down Syndrome	1

Autism	2
Autism with intellectual disability	3
Muscular Dystrophy	1
Osteogenesis Imperfecta	1
Reported Complexity of Needs level*	
High	5
Moderate	5
Low	2
Country of Origin	
Iraq	9
Sudan	2
Syria	1
Educational level	
Associate degree	1
High School Diploma or GED	4
Some High School	5
Some Middle School	1
Some Elementary	1
Work Status	
Not Employed	11
Employed	1
Current Housing	
Living with parents	12

Communication Disability	
Yes	5
No	7
Primary Mode of Mobility	
Ambulant at home, school, and community	8
Wheelchair user at home, school, and community	4
Assistive Technology use	
None	8
Wheelchair	4
Communication Aid	4
Attend Specialty Clinics**	
Neurology	4
Orthopedic	2
Autism	3
Ophthalmology	4
Rehabilitation	3

Note. N= 12. SD = Standard Deviation. * Reported Complexity of Needs Levels: High = reporting functional limitations that require extensive level of support across several life domains, moderate = reporting functional limitations that require intermittent level of support in more than a few life domains, and low = reporting functional limitations that require minimal level of support in few life domains (Thompson et al., 2004). ** Some YIDD attended more than one specialty clinic.

Table 2.3 Demographics Characteristics of Youth Caregivers

Characteristic	N
Age range (years)	
31-40	1
41-50	8
> 51	3
Gender	
Male	0
Female	12
Relationship to youth	
Parent	12
Country of Origin	
Iraq	9
Sudan	2
Syria	1
Education	
Some Middle School	1
Some High School	1
High School or GED	1
Bachelor’s degree	7
Master’s degree	2

Employment	
Not Employed	6
Employed Part Time	5
Employed Full Time	1
Annual Household Income (USD)	
< 24,999	3
25,000 - 49,999	6
50,000 - 74,999	3
Number of people in the household (SD)	4 (1)
Number of people with disability (SD)	1 (1)
Primary Language spoken in the household	8
Arabic only	2
Kurdish and English	1
English only	1
Arabic Kurdish and English	

Note. N= 12. USD = United States Dollars. SD = Standard Deviation

2.4.2 Main Findings

Four main themes emerged from the data: 1) Utilizing resources and support structure to access healthcare, 2) Hurdles to accessing care, 3) Key concerns and priorities in navigating HCT, and 4) Specific needs of Middle Eastern YIDD. Each theme is described below in detail, with supporting quotes from participants.

1) **Utilizing resources and support structure to access healthcare:** Several participants identified different helpful resources that have been instrumental to them in navigating Washington healthcare systems. These included a) Provider specialization and interaction builds trust, b) Access includes transportation, c) Governmental support is key to access, and d) Community information hubs are essential for access. Below, each theme is presented with participants' supporting quotes.

    a) <u>Provider specialization and interaction builds trust:</u> most participants shared that the providers' expertise in their children's specific conditions and disabilities facilitated their care access. For example participant 4's mother shared proudly how she was able to find a skilled and experienced adult provider in her child's condition after extensive search: *"I found a doctor who's really experienced, and especially in P04's case in the [regional center specializing in neurological conditions] for P04's [specific condition] in [city] Dr. [the doctor's name]."* The mother of participant 10 stressed on the significance of providers' skills and positive disability attitudes of care providers towards her daughter saying: *"The uniqueness was in the way they treated her and talked to her in a very kind and respectful way, they gave her the needed information in a way that matched her understanding, and they were very kind in talking to her. This made P10 likes to go for her visits and she really love going to her family medicine doctor because of that. They all know how to talk and address her needs, they know how to deal with P10 and talk to her and to share her issues openly and to express herself well. They treated her as their own daughter not a patient and that made me feel very comfortable for P10 and she was very happy with them. "*

b) Access includes transportation: Subsidized transportation availability was one of the main shared facilitators to healthcare access as several participants perceived this as a facilitator to their healthcare access such as Hopelink which is a non-profit comprehensive program that offers multiple services and assistance programs for families and people with disabilities such as transportation (*Hopelink's Mission*, n.d.). For example, participant 12 said that: *"For far places what do use? we use Hopelink and nearby places my family takes me."* Participant 1's parent shared her transportation positive experience: *"I call the Medicare help line before the appointment by one week or three days and they come same day and they drop me off."*

c) Governmental support is key to access: most of the participants stressed the importance of disability supportive governmental programs including Medicaid, Medicare, Developmental Disabilities Administration (DDA), and Supplemental Security Income (SSI). For example, as participant's 3 mother shared her relief of having several disability supportive programs in Washington: *"Since I came here, I applied for him for Medicaid in the WA state based on our income. We got approved and since then we got a full coverage for his health condition... The Hopelink and the DDA is also a program that you apply for … they assign him a caregiver if he needs and they come to visit him at home and if he wants to work in home the caregiver helps him… there is SSI …and he gets a stipend every month."*

d) Community information hubs are essential for access: Many participants stressed the importance of local community organizations in supporting their healthcare needs by providing valuable connections, counseling services, and information resources during their healthcare access. For instance, participant's 4 mother illustrated how she connected to her new adult care provider saying: *"So the community is my resource ... and, frankly speaking, A [local support services organization] as well ... we go to B [local community activities center] a lot and by chance we will see people with their kids, that's how I knew Dr. [the doctor who wound up seeing my child]"*. Participant's 6 mother also shared that her son's job was facilitated through the help and support of local organization connection and their case manager's individualized plan: *"[a local support organization that offers disability supportive programs, employment options, and counseling services] helped me a lot, helped me in like the current situation with his job with his community engagement, making that personal centered plan."*

2) **Hurdles to accessing care:** Three main reported healthcare access obstacles were shared by the majority of participants these are: a) The monster of healthcare affordability (Insurance), b) Communication struggles, and c) Delayed specialized care frustrations. These are detailed below with the supporting quotes.

a) <u>The monster of healthcare affordability (Insurance):</u> This was the leading barrier with the majority of participants sharing that they faced numerous issues with insurance coverage for needed medications and services that were essential for their children. This was a prominent problem with dental care, specialized therapies, medications, and devices. For example, Participant 2's mother said: *"P2 has curvature in his legs, and we went to a doctor to check on this and when we booked at a specialty clinic, we went there and they did not accept the [public] insurance, so we tried physical therapy…many times we went to other clinics and they said that the insurance does not cover the orthosis because he is almost walking on the dorsum of his foot… but we did not get any attention."*

b) <u>Communication struggles:</u> This was reported by many participants who consistently shared that they faced communication challenges with some healthcare providers. This included misunderstandings due to language differences and use of medical terms during care interactions that were not familiar to them especially during their first years of settlement in Washington. Participant 8's mother said: *"The big issue I faced this in the beginning, the language barrier, the language barrier is the big issue because this is not my mother Language… Now I've more English … and this has helped me to understand some more so, this is the big issue I faced in the beginning…I cannot understand what, for example, like how I access this program, what I need to do, how I can search even the simple stuff. I cannot, you know, reach them easily. So if you request an interpreter … sometimes they provide you with the interpreter with different accents, and they don't have experience with things like autism, or that case with special needs … so I'm struggling a lot with the interpreter … after that day I decided to learn by myself. I enroll myself in ESL classes (English second language), and attend the classes … I translate by myself to learn about those medical terms regarding my son's situation, so it's really hard.*"

c) <u>Delayed specialized care frustrations:</u> The long waiting times for specialized healthcare services was a challenge for three participants, as these families experienced extensive waiting times for essential services, especially for specialized therapies such as applied behavioral therapy and speech. Participant's 9 mother shared: *" So I [had a] very hard time to find therapist for her especially about her behavior … imagine more than 7 years on waiting list to get like ABA therapy for her… [It was] a different case about speech therapy, I was so lucky because someone cancelled and they asked me to bring P09 to her* *appointment at 7 am. I have to drive from Seattle to Kent around 45 min … 3 times a week just to take P09 to the same place …just to get speech therapy. It's very hard for kids who have autism or are disabled to get access to these thing especially ABA, Speech, or OT...So again, 7 years, just to get ABA, and honestly more than 7 years [to wait] and she just got 2 or 3 years, and after that they stopped because she already turned 14."*

3) **Key concerns and priorities while navigating HCT:** This theme include two main shared concerns and priorities during HCT process. These were: a) Continuity of care and trust, and b) Comprehensive and tailored care. These sub themes are described below with supporting quotes from participants:

    a) <u>Continuity of care and trust:</u> Most of the participants were worried about HCT process as they had to move to a new and unfamiliar adult provider. Many said that they were concerned because the new adult care providers might not know their child's medical history and needs well as their current pediatric care providers. The mother of participant 1 shared her fear from the unknown HCT result, describing*:* *"Our fears are not much but we are afraid of her wellbeing when is she going to a new healthcare [adult cares settings and providers] that we do not know anything about. The previous ones [pediatric care providers]who know her left her, like her dentist and physiotherapist, this is their clinic policy. But for us we are going into the unknown"*. Participant's 7 parent articulated her trust concerns saying: *"Oh I think my biggest concern will be like trust, I think trust, finding a healthcare provider who I can trust and a primary care provider who is familiar with kids like participant 7 and are able to at least have the info, like the necessary information and the connections to be able to direct us."*

b) Comprehensive and tailored care: This was the second concern raised by six participants. These participants highlighted the significance of comprehensive, resourceful and tailored care to address their children's specific needs. They shared concerns about communication strategies between healthcare providers, medication management, and support to maintain their children's health and quality of care. The mother of participant 4 stressed having resourceful clinics and providers during HCT saying: *"I would like for P04 to find, when we transition, my goal is to find her a clinic that, first of all, appreciates her disability, has a friendly environment, a good resourceful clinic or provider. And by resourceful, I mean to find ways to communicate with participant 4, make her do follow up with her healthy life in a proper way."* Participant 6's mother further shared: *"For the doctors to be considerate … I'm thinking, if in the future, if we are not there, I hope the care providers… I hope they will focus more on their instructions, be more detailed, because for now I feel like I am pushing everything … I was thinking of people who don't have that kind of support, or say they are families like us, all of us from the Middle East or from any other country. We don't know how to communicate, we don't know how to go on [the online portal for the] chart and write these requests."*

4) **Key needs during HCT:** Three main specific needs emerged for the participating families these were: a) Communication is the priority, b) Engagement in healthcare decisions, and c) Specialized care needs and recreational activities. These sub themes are detailed below with supporting quotes.

a) Communication is the priority: Many families shared that they need better communication and preparation for HCT to include clear and detailed HCT information from healthcare providers as early as possible. This communication should include the HCT stages, care changes, any plans, and new healthcare locations. For example, the parent of participant 12 stated: *" I want them, the healthcare team, to provide me ... all details about that and clear details…don't … just move me without enough knowledge, I want to know- me and the dad and P12- what's going to happen? What are the steps? And where is he going to be."* Another mother shared her frustration resulting from the lack of HCT preparation, saying: *"They just said that she can no longer come here and that she is older and an adult now, she needs to see an adult care provider...no one talked about HCT and [there was] no planning at all. I was sitting after the appointment in the car thinking, 'Where should we take her?' ... Where, after 6 months she needs a new appointment, where should we go?!"* (participant 1's mother). Other families requested that healthcare providers be trained in disability related communication skills, as the parent of participant 4 shared*: "There is one big thing I really would like… a clinic that appreciates special needs. Like the doctor … like all doctors in general …I'm sure there should be some kind of training for any doctor … how to treat patients in general, but there should be specific workshops that could be held yearly and be obligatory for all health providers to attend to know how to practice … their specialty with kids with special needs… young adults with special needs."*

b) <u>Engagement in healthcare decisions:</u> Several families described the need for shifting the traditional norm of passively accepting the healthcare providers recommendations. Participant's 7 mother shared: *"I know where we come from* *[country]…people have this blind trust in professionals like built in if the doctors say do this, they will just do it without even questioning. Here [in the US] it's a different thing, I think you need to be the one who is at least an important part of the decision, and not just take whatever they put in front of you, you can ask questions think about things."*

c) Specialized care needs and recreational activities: Various families shared their need for specialized care and after school leisure activity programs for their children. Participant's 9 parent said: *"She needs a lot again, she needs someone… like before she was receiving ABA… for behavior and they stopped … she didn't receive anymore because of her age… [It would be helpful to] send someone …to stay with P09 or teach her … physically and mentally."* Participant's 11 parent shared similar thoughts, stating *"They need more activities… they do not have many options for out of school activities. Now my daughter has no activities, she only goes to school or stays at home all the time."*

2.5 Discussion

This study provides valuable knowledge about the experiences of Middle Eastern YIDD and their families in Washington State regarding their healthcare access and HCT processes. Four main themes emerged, which are: Utilizing resources and support structure to access healthcare, hurdles to accessing care, key concerns and priorities while navigating HCT, and key needs during HCT. Providers specialization and interactions builds trust, access including transportation, and governmental support is key, community information hub are essential for access were the main sub themes for utilizing resources and support structure to access Washington healthcare systems. Conversely, barriers to access were led by the monster of healthcare affordability (health insurance), communication struggles, and delayed specialized care frustrations. During HCT, the families' key concerns were care continuity and trust, and obtaining comprehensive tailored care. The prioritized needs were communication is the priority, engagement in healthcare decision making, and specialized care needs and recreational activities.

The intersectionality of these participants identities during their healthcare access and transitioning revealed intricate experiences that are unique to the US context. Despite the shared utilization of care resources and other support structure by Middle Eastern YIDD and their families, they still face unique challenges when accessing US healthcare systems these included health insurance issues, communication struggles, and delays in specialized care.

The specialized healthcare providers and their positive interactions with Middle Eastern participants enriched their experiences. This sub theme aligns with studies that reported the value of care providers' knowledge and familiarity with the specific challenges faced by immigrants' families in the US including language, transportation, and documentation, while working actively to address these challenges proactively (Abudiab et al., 2023; Bogenschutz, 2014). This emphasizes the value of such providers in healthcare systems that serve diverse populations in the US. The providers specialization and the communication struggle sub themes of care access align with some of the previous research on non-Middle Eastern immigrants and refugees with intellectual and developmental disabilities in the US. Bogenschutz (2014) found that culturally and linguistically sensitive providers along with supportive systems facilitated healthcare access, while barriers encompassed difficulties in finding accurate information on insurance and providers, issues with coordinating multiple specialty appointments, and lack of cultural competence (Bogenschutz, 2014). However, Bogenschutz's study focused on a broader pool of immigrants and refugees and did not specifically investigate Middle Eastern population. It also included a broader age range of participants from 2 to 23 years, while this study only included youth participants.

The availability of disability supportive governmental and community organizations (Washington State Hospital Association, 2024; Yen, 2010) was appreciated by the Middle Eastern families which suggests that these are valuable resources for supporting Middle Easten YIDD and families during their healthcare access and HCT. This stresses the need for sustaining these resources and developing partnerships with such organizations to optimize healthcare support and experiences of this population.

Language support services are integral for healthcare access of immigrants and refugees populations (Khoong & Fernandez, 2021). The shared communication struggles shared by most participants highlight this issue as one of the main barriers to healthcare access for this population especially at their early settlement time in the US. Limited English fluency delays healthcare access and hinders building effective relationships between patients and care providers (Pandey et al., 2021). There is also evidence that patients with limited English language proficiency might not seek clarifications when they do not understand instructions, or even advocate for their own needs, this might increase misunderstandings during healthcare communication (Pandey et al., 2021). This challenge might also be a significant obstacle to receiving a better quality of care (Pandey et al., 2021). Hence, providing interpreters to Middle Eastern immigrants and refugees families could enhance their experiences and promote communication, especially during their early immigration time in the US (Khoong & Fernandez, 2021). There is also a need for policy makers to address the shared health insurance coverage issues and specialized care attainment issues faced by most participants as this impacts their healthcare experiences.

Surprisingly, HCT planning and preparation was evidently inadequate based on the shared key needs and concerns of these participants. This is concerning in light of the other contextual factors and challenges faced by these participants. This finding contrasts with the growing literature that emphasizes on having a structured HCT process for YIDD (Betz, 2023; Betz et al., 2016) and the benefits of HCT in improving patients' health outcomes (Levy et al., 2020). This also contradicts with the HCT guidelines and recommendations to start planning and preparation as early as twelve years of age (Turchi et al., 2024). This finding reveals the gap between HCT best practice guidelines and implementation. This highlights the need for implementing HCT guidelines and best practice recommendations to improve the Middle Eastern HCT experience.

2.6 Limitations

This study has many limitations including the small sample size both in number and country of origin, which does not fully represent the Middle Eastern population in the US. Further, participants recruitment was challenging due to many factors including cultural stigma that is associated with disability (Javaid, 2024). This was mitigated by working with a trusted community partner (ODMF) and by stressing confidentiality and privacy of research participants. However, this recruitment strategy might present selection bias to the study sample which potentially overrepresented those who are connected to this local community organization.

The fact that only three YIDD were actively involved in the discussions is another limitation, despite an explicitly communicated desire for the youth to be active participants in the conversations. This may be due to communication difficulties such as differing dialect between the researcher and participants. Moreover, participants with severe complexity of needs and complex impairments faced challenges in understanding research questions and engaging socially, which could have limited their active involvement in interviews. Finally, the hour-long interviews may have affected the attention span of youth participants, which further limited their participation. These factors limited the full representation of YIDD perspectives in data analysis and thematic development, skewing the findings towards caregivers' perspectives. Future studies need to employ effective engagement strategies and consider doing shorter individualized interviews with YIDD while using visual aids and assistive communication technologies to promote active youth participation and to fully capture their perspectives while accommodating their needs.

Despite these limitations, this study has notable strengths including conducting bilingual interviews using either Arabic or English, which allowed the incorporation of Arabic speaking participant experiences as a significant contribution to the diversity of voices represented in HCT literature. Another strength is the diverse lived experience within the participant pool through incorporating a wide range of care needs and medical diagnoses. This allowed for capturing a broader spectrum of Middle Eastern YIDD experiences.

2.7 Conclusion

This study provided valuable insight into the experiences of Middle Eastern YIDD and their families while accessing the US healthcare system in Washington State. It identified many positive experiences such as specialized providers and supportive organizations, it revealed many challenges in insurance coverage, communication, and HCT planning. It also identified the key priorities, concerns, and needs during HCT. While the sample was small, this study provided a valuable snapshot of the experiences of this population to inform future research and policy makers who are interested in providing inclusive and supportive healthcare services to the Middle Eastern population.

2.8 Bibliography

Aboul-Enein, B. H., & Aboul-Enein, F. H. (2010). The cultural gap delivering health care services to Arab American populations in the United States. Journal of Cultural Diversity, 17(1).

Abudiab, S., de Acosta, D., Shafaq, S., Yun, K., Thomas, C., Fredkove, W., Garcia, Y., Hoffman, S. J., Karim, S., Mann, E., Yu, K., Smith, M. K., Coker, T., & Dawson-Hahn, E. (2023). “Beyond just the four walls of the clinic”: The roles of health systems caring for refugee, immigrant and migrant communities in the United States. Frontiers in Public Health, 11. https://doi.org/10.3389/fpubh.2023.1078980

Alarcon, F. J. (2022). The migrant crisis and access to health care. Delaware Journal of Public Health, 8(4), 20.

Andersen, R. M., Davidson, P. L., & Baumeister, S. E. (2007). Improving access to care in America. Changing the US Health Care System: Key Issues in Health Services Policy and Management. 3a. Edición. San Francisco: Jossey-Bass, 3–31.

Ando, H., Cousins, R., & Young, C. (2014). Achieving saturation in thematic analysis: Development and refinement of a codebook. Comprehensive Psychology, 3, 03-CP.

Anwer, A. (2022). THE AMERICAN DREAM AND MUSLIM AMERICANS. The Routledge Handbook on the American Dream: Volume 2.

Asbu, E. Z., Masri, M. D., & Kaissi, A. (2017). Health status and health systems financing in the MENA region: roadmap to universal health coverage. Global Health Research and Policy, 2, 1–13.

Betz, C. L. (2023). Health care transition planning for adolescents and emerging adults with intellectual disabilities and developmental disabilities: Distinctions and challenges. Journal for Specialists in Pediatric Nursing, 28(3), e12415.

Betz, C. L., Coyne, I., & Hudson, S. M. (2021). Health care transition: The struggle to define itself. Comprehensive Child and Adolescent Nursing, 1–15.

Betz, C. L., O’Kane, L. S., Nehring, W. M., & Lobo, M. L. (2016). Systematic review: Health care transition practice service models. Nursing Outlook, 64(3), 229–243.

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: a tool to enhance trustworthiness or merely a nod to validation? Qualitative Health Research, 26(13), 1802–1811.

Björquist, E., Nordmark, E. A. K., Almasri, N. A., & Kristensson Hallström, I. (2017). Immigrant Youths with Disabilities and Caregivers from the Middle-East—Challenges and Needs During Transition to Adulthood. Research in Health Science, 2(4), 363–384.

Blumenthal, D., Gumas, E., & Shah, A. (2024). Mirror, mirror 2024: a portrait of the failing US health system.

Bogenschutz, M. (2014). “We find a way”: challenges and facilitators for health care access among immigrants and refugees with intellectual and developmental disabilities. Medical Care, 52, S64–S70.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.

Brown, M., Macarthur, J., Higgins, A., & Chouliara, Z. (2019). Transitions from child to adult health care for young people with intellectual disabilities: A systematic review. Journal of Advanced Nursing, 75(11), 2418–2434.

Creswell, J. W., & Poth, C. N. (2016). Qualitative inquiry and research design: Choosing among five approaches. Sage publications.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. Journal of Advanced Nursing, 62(1), 107–115.

Gibson, B. E., Mistry, B., Smith, B., Yoshida, K. K., Abbott, D., Lindsay, S., & Hamdani, Y. (2013). The integrated use of audio diaries, photography, and interviews in research with disabled young men. International Journal of Qualitative Methods, 12(1), 382–402.

Gréaux, M., Moro, M. F., Kamenov, K., Russell, A. M., Barrett, D., & Cieza, A. (2023). Health equity for persons with disabilities: a global scoping review on barriers and interventions in healthcare services. International Journal for Equity in Health, 22(1), 236.

Hopelink’s Mission. (n.d.). N.d. Retrieved November 28, 2024, from https://www.hopelink.org/about-us/

Javaid, S. F. (2024). Disability Stigma in the Middle East. In The Palgrave Encyclopedia of Disability (pp. 1–6). Springer.

Joo, J. Y., & Liu, M. F. (2021). Culturally tailored interventions for ethnic minorities: A scoping review. Nursing Open, 8(5), 2078–2090. https://doi.org/10.1002/nop2.733

Katoue, M. G., Cerda, A. A., García, L. Y., & Jakovljevic, M. (2022). Healthcare system development in the Middle East and North Africa region: challenges, endeavors and prospective opportunities. Frontiers in Public Health, 10, 1045739.

Khoong, E. C., & Fernandez, A. (2021). Addressing gaps in interpreter use: time for implementation science informed multi-level interventions. Journal of General Internal Medicine, 36(11), 3532–3536.

Kuehn, B. M. (2021). US health system ranks last among high-income countries. JAMA, 326(11), 999.

Lebrón, A. M. W., Torres, I. R., Kline, N., D LOPEZ, W., YOUNG, M. D. E. T., & Novak, N. (2023). Immigration and immigrant policies, health, and health equity in the United States. The Milbank Quarterly, 101(Suppl 1), 119.

Levy, B. B., Song, J. Z., Luong, D., Perrier, L., Bayley, M. T., Andrew, G., Arbour-Nicitopoulos, K., Chan, B., Curran, C. J., & Dimitropoulos, G. (2020). Transitional care interventions for youth with disabilities: a systematic review. Pediatrics, 146(5).

Mahan, J. D., Betz, C. L., Okumura, M. J., & Ferris, M. E. (2017). Self-management and transition to adult health care in adolescents and young adults: a team process. Pediatrics in Review, 38(7), 305–319.

Marks, R., Jacobs, P., & Coritz, A. (2023). Lebanese, Iranian and Egyptian populations represented nearly half of the MENA population in 2020 Census. US Census Bureau.

Massachusetts, U. S. (2023). NVivo [Computer software] (14). QSR International.

Mate, K., Bryan, C., Deen, N., & McCall, J. (2017). Review of health systems of the Middle East and North Africa Region. International Encyclopedia of Public Health, 347.

Merriam, S. B., & Tisdell, E. J. (2015). Qualitative research: A guide to design and implementation. John Wiley & Sons.

Mirza, M., Luna, R., Mathews, B., Hasnain, R., Hebert, E., Niebauer, A., & Mishra, U. D. (2014). Barriers to healthcare access among refugees with disabilities and chronic health conditions resettled in the US Midwest. Journal of Immigrant and Minority Health, 16, 733–742.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. International Journal of Qualitative Methods, 16(1), 1609406917733847.

Pandey, M., Maina, R. G., Amoyaw, J., Li, Y., Kamrul, R., Michaels, C. R., & Maroof, R. (2021). Impacts of English language proficiency on healthcare access, use, and outcomes among immigrants: a qualitative study. BMC Health Services Research, 21(1), 741. https://doi.org/10.1186/s12913-021-06750-4

Peel, K. L. (2020). A beginner's guide to applied educational research using thematic analysis. Practical Assessment, Research, and Evaluation, 25(1), 2.

Read, J. G., Ajrouch, K. J., & West, J. S. (2019). Disparities in functional disability among Arab Americans by nativity, immigrant arrival cohort, and country of birth. SSM - Population Health, 7, 100325. https://doi.org/10.1016/j.ssmph.2018.100325

Shaimaa, E., & Bialous, S. (2024). Mental Health Care Access Among Arab Immigrants in the United States: Application of Public Arena Model. Community Mental Health Journal, 60(2), 376–384.

Simaroj, P., Phol, R., Chalalai, S., & Phol, R. (2023). Barriers to the Uptake of Cataract Surgery in Lumbini Nepal and Aranyaprathet Thailand. The Bangkok Medical Journal, 19(2), 134.

Squires, D., & Anderson, C. (2015). US health care from a global perspective: spending, use of services, prices, and health in 13 countries. Issue Brief (Commonwealth Fund), 15, 1–15.

Svensson, H. (2024). Language dynamics and agency in multilingual research interviews. International Journal of Applied Linguistics, 34(3), 1058–1073. https://doi.org/10.1111/ijal.12555

Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., & Rotholtz, D. A. (2004). Support intensity scale. *Supports Intensity Scale Users Manual. Washington, DC: American Association on Mental Retardation*.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. Qualitative Inquiry, 16(10), 837–851.

Turchi, R. M., Kuo, D. Z., Rusher, J. W., Seltzer, R. R., Lehmann, C. U., & Grout, R. W. (2024). Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities: Policy Statement. Pediatrics, e2024066841.

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Medical Research Methodology, 18, 1–18.

Washington State Hospital Association. (2024). New Program: Apple Health Expansion (AHE) for Undocumented Residents. https://www.wsha.org/policy-advocacy/issues/coverage-for-undocumented-individuals-in-washington-state/

Wilson, F. A., & Stimpson, J. P. (2020). Federal and state policies affecting immigrant access to health care. JAMA Health Forum, 1(4), e200271–e200271.

Yen, W. (2010). Health Coverage Disparities Associated with Immigration Status in Washington State's Non-elderly Adult Population: 2010-17. Washington State Health Services Research Project. Washington State Office of Financial Management; May 2019 2019. The Washington State Office of Financial Management (OFM) Provided a Summary of Health Coverage From.

Zagloul, M., Mohammed, B., Abufares, N., Sandozi, A., Farhan, S., Anwer, S., Tumusiime, S., & Bojang, M. (2024). Review of Muslim Patient Needs and Its Implications on Healthcare Delivery. Journal of Primary Care & Community Health, 15, 21501319241228740.

Chapter 3. Healthcare Transitioning Barriers and Facilitators from the perspectives of Middle Eastern Youth with Disabilities and their families in Washington State

3.1 Abstract

Introduction: Previous healthcare transition (HCT) research indicates that immigrant and refugee children with intellectual and developmental disabilities face unique challenges during HCT with limited evidence about the specific needs of the Middle Eastern population in the United States during this critical time. This study aimed to explore current HCT facilitators and barriers from the perspectives of Middle Eastern youth with intellectual and developmental disabilities (YIDD) in Washington State. **Method:** Photovoice narrative method was utilized using a list of guiding questions with eleven Middle Eastern YIDD and their families. Interviews were analyzed using NVivo software and inductive thematic analysis then followed by member checking. **Results:** Healthcare providers' support; supportive healthcare facilities and clinics; independence and personal growth; and providers' cultural competence emerged as key HCT facilitators. Health insurance coverage issues; lack of HCT planning, preparation, resources; independence and readiness to lead challenges; and gender-specific preferences were the main resulting HCT barriers. **Conclusion/Discussion:** These results highlight the need for implementing HCT best practice and guidelines to improve the HCT experience for this population in the United States. Photovoice narrative method may be a powerful tool to empower families and communicate their needs and challenges of this under-represented community in the United States.

3.2 **Introduction**

In the United States (US), youth with intellectual and developmental disabilities (YIDD) encounter significant challenges when transitioning from the pediatric to adult care services. This process is known as Healthcare Transiting (HCT) and is particularly challenging for groups coming from minority backgrounds including Middle Eastern communities. Commonly, families and young children with intellectual and developmental disabilities (IDD) have access to various resources and services during early childhood and across their lifespan in US context (Guralnick, 2007; Hewitt et al., 2013; Vohra et al., 2014), however, when these children transition into adulthood, they face complex and fragmented healthcare system especially for those who are new to the US healthcare system (Eneriz-Wiemer et al., 2014; Lotstein et al., 2010; Robards et al., 2018). While a significant body of research has focused on the needs of children with IDD, there is a growing recognition of the unique challenges faced by youth with IDD (YIDD) during HCT *(Betz, 2023; Hobart & Phan, 2019; Tyler Jr & McDermott, 2021)*.

To understand these challenges, it is important to focus on HCT. HCT is defined as the transfer process of patients from the pediatric to the adult care services through collaborative efforts of effective planning, actual transfer and integration into adult care systems (Betz et al., 2021). This process forms a critical phase for youth with IDD (Betz, 2023). HCT is particularly challenging for Middle Eastern YIDD and their families who may face unique cultural, linguistic, and systemic barriers when accessing healthcare in the US (Aboul-Enein & Aboul-Enein, 2010; Ezenkwele & Roodsari, 2013; Minority Rights Group International, n.d.). While research on HCT has grown in recent years, there is an evident gap in understanding the specific experiences of YIDD from minority groups in the US .

Globally, HCT of YIDD has been explored primarily using descriptive analyses, and a concern of this work is the limited input from the population themselves (Betz et al., 2016; Brown et al., 2019; Kaehne et al., 2019). A systematic review explored the nature of the available evidence on HCT for youth with intellectual disabilities through investigating study designs and methodology, found that HCT research was mainly exploratory in nature and lacks direct involvement of those youth with problematic absence of participatory action research (PAR) in this area (Kaehne et al., 2019). Another systematic review highlighted the need for HCT research focusing on youth with complex medical conditions such as YIDD disabilities (Schmidt et al., 2020).

Although the impact of PAR has been recognized in engaging and empowering people with IDD in research, evidence on utilizing it for YIDD is limited (Jurkowski, 2008). This limitation is prominent in research studies involving IDD minority populations in the US including Black, Latinx/Hispanic, American Indian, and Asian individuals (Williamson et al., 2023). PAR framework has been used successfully but sparingly in research and have been called for in greater frequency with minoritized populations, including people with disabilities, to amplify their voices and improve their healthcare access and equity (Balcazar et al., 2006; Baum et al., 2006; Kester et al., 2021; Pain et al., 2019; Suprapto et al., 2020). However, to the best of our knowledge, there are no studies that have used PAR with Middle Eastern YIDD and their families during HCT (De Abreu Lourenço et al., 2021; Kaehne et al., 2019; Schmidt et al., 2020). Capturing the perspectives of this multiply marginalized population and their caregivers during HCT is vital to effectively develop and implement HCT programs (Okumura et al., 2015).

Children with IDD from racial and ethnic minorities face healthcare disparities due to their disability status and minority background (Bishop-Fitzpatrick & Kind, 2017; Zuckerman et al., 2013, 2017). This intersection creates further challenges in healthcare access (Bishop-Fitzpatrick & Kind, 2017). Moreover, immigration status forms a unique social health determinant (Castañeda et al., 2015). A scoping review found that Latino immigrant families of children with IDD face many disparities to healthcare access in US highlighting the lack of studies investigating other immigrants' groups (Xu et al., 2022), such as those from Middle Eastern origin. For many refugees and immigrants in the US, HCT can be particularly challenging due to language barriers, cultural differences, and lack of knowledge about the US healthcare systems (Abudiab et al., 2023; Mohammed, 2022).

Hence, this study aimed to explore the current barriers and facilitators to HCT from the perspectives of Middle Eastern YIDD and their caregivers in Washington State using PAR methodology.

3.3 Methods

All study procedures were conducted with ethics approval from the University of Washington Human Subjects Division (IRB ID # STUDY00019215). Prior to participating in any research activities, all participants provided informed consent, caregiver permission, and/or assent. Photo releases were obtained as part of the consent process. Recruitment challenges were mitigated through working with a community partner organization (Open Doors for Multicultural Families) and by building rapport and trust between potential participants and the researcher, who was an insider in the community. Issues related to privacy were addressed by stressing confidentiality, discussing concerns, and offering photos blurring option to those who were hesitant to participate.

The research visit involved one researcher (Abuatiq), the Middle Eastern YIDD and one caregiver. The visits were conducted either in Arabic (the native language of participants) or English based on participants' preference. All interviews were audio recorded and transcribed verbatim into both Arabic and English. The Arabic interviews were subsequently translated into English. This study involves holding a community photo exhibit to share the findings with the local community.

PAR is a research framework that is useful for amplifying the lived experiences of minority groups while simultaneously minimizing power differential between researchers and participants (Kindon et al., 2007; Pain et al., 2019). This framework aims empower and engage communities in addressing challenges, while the researcher acting as a facilitator and collaborator rather than an outsider (Cahill, 2007; Grant et al., 2008). In this study we used the photovoice narratives method, a commonly used PAR method. Photovoice narratives offer a unique technique for understanding HCT, as it provided an inclusive and accessible research approach (Walton et al., 2012).The benefits of photovoice are not limited to alleviating communication barriers, they extend to active engagement in the research process (Lal et al., 2012).

Photovoice narratives were conducted with Middle Eastern YIDD-caregiver dyads. During a one-hour visit, Middle Eastern YIDD-caregiver dyads were given written and verbal instructions for the photovoice narratives. For families who did not have access to a smart phone, digital cameras with memory cards were provided. Participants were asked to take photographs of events, places, or individuals that they consider significant and related to the following specific research questions focused on HCT experience, which were provided in a guide to each family (Burke, 2012; Merriam & Tisdell, 2015; Sutton-Brown, 2014) in Table 3.1:

Table 3.1 Sample Photo Narratives Questions Guide

• Take a photo of a place or person that has supported you/your child during healthcare transition
• Take a photo of something that has been a barrier to your child's healthcare transitioning
• Take a photo that shows your child participating in an activity that is important to your family
• Take a photo that shows how your cultural background has affected your healthcare transitioning experiences and needs

This question guide was created through discussions with the community partner representative and the researcher's academic advisor. Power dynamics between the researcher and participants were evident at the beginning of this research study due to the prevalent cultural norms of respecting and valuing clinicians and researchers as experts. However, this was shifted through open and ongoing communication focused on recognizing the value of the participants' lived experiences. This was achieved by explaining the goals of the PAR framework and encouraging participants to share their own stories as co-researchers. It was also important to emphasize the participants' full control of which photos were taken and selected. This shift took time to achieve but eventually participants realized the purpose of this study and enjoyed the process.

The participants had full control over the photo content and quantity, however there was a suggested minimum of 3-5 photos for each guiding question. They then selected which photographs they believed were most important or meaningful. A final research visit took place around 1-2 months after sharing the photo narrative guide. During this final visit, participants shared their descriptive narratives of the selected photos using a participant-led analysis using the SHOWED question protocol (Wang & Burris, 1997). This protocol uses five key questions to effectively facilitate photovoice discussions (Komaie et al., 2018), these are:

1- What do you See here?
2- What is really Happening?
3- How does this relate to Our lives?
4- Why does this situation, concern, or strength exist?
5- How can we become Empowered by our new understanding?
6- What can we Do about it?

This protocol was successfully used previously in health research and other fields (Anderson et al., 2023). These questions ask participants about what they see, what is really happening, how this relates to HCT, and why this situation, concern, or strength exists. These visits were audio-recorded, transcribed verbatim, and translated into English.

3.3.1 Data collection

3.3.2 Participants

Participants were recruited by distributing the study flyers via emails, social media, and a local community organization (Open Doors for Multicultural Families). This non-profit organization offers support services and programs for individuals with intellectual and developmental disabilities from diverse cultural backgrounds. To facilitate recruitment, the researcher partnered with a case manager from this organization. The inclusion criteria for youth participants were: Middle Eastern immigrants residing in Washington State; aged 14-24 years, any gender, have an intellectual or developmental disability, and able to participate in a one-hour research visit in-person or via zoom. Caregivers' inclusion criteria were: Age 18 or older, the legal guardian of Middle Eastern YIDD, lived in the same household as the Middle Eastern YIDD and familiar with taking pictures using smartphones or digital cameras, in case the Middle Eastern YIDD is not familiar with picture taking.

3.3.3 **Data analysis**

Data analysis of the photo narrative transcripts was ongoing and conducted using the inductive thematic analysis method (Braun & Clarke, 2006; Elo & Kyngäs, 2008; Peel, 2020) which consisted of independent analysis by the researcher using open and focused coding until themes emerged. NVivo qualitative analysis software was used to help organize and label codes and themes (Massachusetts, 2023). After the initial thematic analysis, a streamlined member checking process was conducted to enhance the credibility and trustworthiness of the findings (Birt et al., 2016). This process involved preparing a concise summary of the main emerging themes and supporting data. This summary was shared with all participants via email for review. Then a brief follow-up phone call of 15 minutes was conducted with each participant. The following focused validation questions were asked: 1) Do these themes accurately reflect your experiences? 2) Is there anything important missing or that should be changed? Notes were taken during each call and immediate review of the themes was done after the call to ensure comprehensive documentation of participant feedback. The feedback was analyzed for consistency and concerns about the preliminary themes. Based on this analysis, the themes were refined, incorporating participant feedback. This ensured that the resulting themes were aligned with the participants' lived experiences. This validation process ensured that participants had an opportunity to confirm or clarify themes enhancing the credibility of this analysis (Tracy, 2010).

Additionally, to ensure the data collection and analysis rigor, the researcher adhered to the principle of unconditional positive regard to create supportive and non-judgmental environment (Farber et al., 2018). The insider positionality of the researcher, as a Middle Eastern community member, added valuable contextual knowledge and facilitated rapport building, which in turn enriched the depth of collected data and translation (Dwyer & Buckle, 2009).

3.4 Results

3.4.1 Demographic Data

Eleven Middle Eastern youth and families participated in this study. Tables 3.2 and 3.3 contain demographic data of the youth and caregiver participants. All participating caregivers were the parents of the YIDD.

Table 3.2 Demographics and Clinical Characteristics of Youth Participants

Characteristic	N
Age, years	
Mean (SD)	18.2 (3.3)
Range	14 – 24
Gender	
Male	6
Female	5
Medical Diagnosis	
Cerebral Palsy	4
Down Syndrome	1
Autism	2

Autism with intellectual disability	2
Muscular Dystrophy	1
Osteogenesis Imperfecta	1
Reported Complexity of Needs level*	
High	4
Moderate	5
Low	2
Country of Origin	
Iraq	9
Sudan	1
Syria	1
Educational level	
Associate degree	1
High School Diploma or GED	3
Some High School	5
Some Middle School	1
Some Elementary	1
Work Status	
Not Employed	10
Employed	1
Current Housing	
Living with parents	11
Communication Disability	

Yes	4
No	7
Primary Mode of Mobility	
Ambulant at home, school, and community	7
Wheelchair user at home, school, and community	4
Assistive Technology use	
None	5
Wheelchair	4
Communication Aid	4
Specialty Clinics**	
Neurology	4
Orthopedic	2
Autism	2
Ophthalmologists	4
Rehabilitation	3
Transportation Mode	
Family Car	6
Hope link	2
Both	3

Note. N= 11. SD = Standard deviation. * Reported Complexity of Needs Levels: High = reporting functional limitations that require extensive level of support across several life domains, moderate = reporting functional limitations that require intermittent level of support in more than a few life domains, and low = reporting functional limitations that require minimal level of support in few life domains (Thompson et al., 2004). ** Some YIDD attended more than one specialty clinic.

Table 3.3 Demographics Characteristics of Youth Caregivers

Characteristic	**N**
Age range (years)	
31-40	1
41-50	7
> 51	3
Gender	
Male	0
Female	11
Country of Origin	
Iraq	9
Sudan	1
Syria	1
Education	
Some Middle School	1
Some High School	1
High School or GED	1
Bachelor’s degree	6
Master’s degree	1

Employment	
Not Employed	5
Part Time	5
Full Time	1
Annual Household Income (USD)	
< 24,999	3
25,000 - 49,999	6
50,000 - 74,999	2
Number of people in the household (SD)	4 (1)
Number of people with disability (SD)	1 (1)
Primary Spoken Language in the household	
Arabic only	7
Kurdish and English	2
English only	1
Arabic Kurdish and English	1

Note. N= 11. USD = United States Dollars. SD = Standard Deviation.

3.4.2 Main Findings

The resulting themes were classified into two main themes: HCT facilitators and barriers. **The main HCT facilitators** were summarized into four key subthemes. These are:

1. Healthcare Provider Support: emerged as the leading theme with the majority of participants. This encompassed having providers who are supportive, understanding, cooperative, and knowledgeable about HCT. These families perceived a trusting healthcare provider relationship as valuable and fundamental, with many families

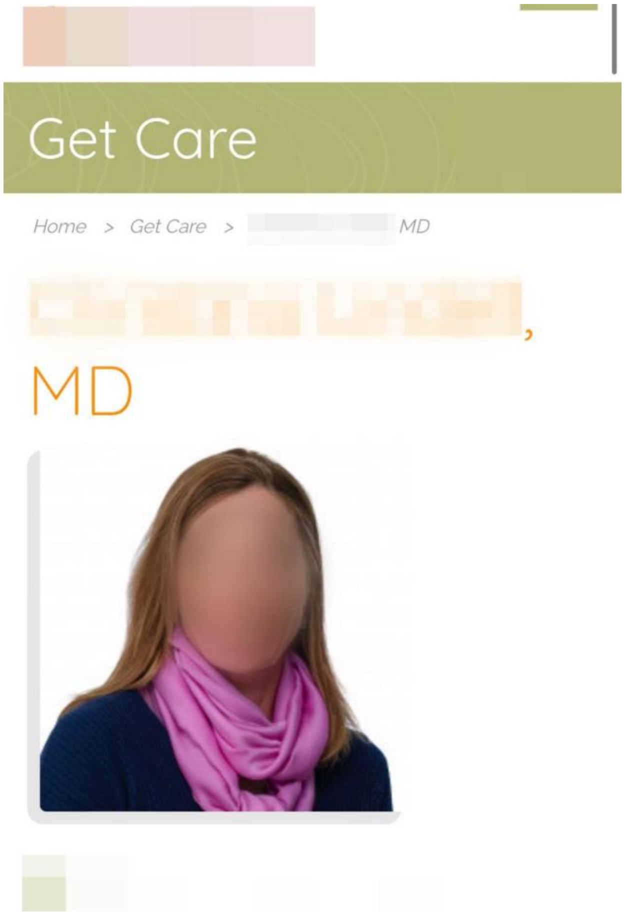
stressing the importance of having such relationships during HCT process. These families shared how valuable it is for them to feel comfortable and not to be judged on their disabilities. Positive patient-provider relationships nurtured trust and feelings of safety during HCT and allowed participants to progress smoothly at their own pace. This theme is illustrated by this youth participant who shared Figure 3.1 stating:

Figure 3.1

Participant 11: *"I just feel really comfortable with her, I have known her since I was a child and she supported me and she has helped me a lot and never judge[s] me… I am always in my own comfort zone with her … if I am too scared to do something she takes her time with me…when I tell her that I'm scared, 'Can you hold me?' … she will do it in a heartbeat."*

Another parent shared a photo of one of their healthcare providers, narrating Figure 3.2:

Figure 3.2



Get Care

Home > Get Care > [redacted] MD

[redacted],
MD

Participant's 12 parent: *"She's helping... and guiding us what to do on the transfer of Participant 12 from [one] to the other one to get the adult health care services."*

Another parent shared a screenshot of her daughter's healthcare provider's contact information in Figure 3.3 commenting:

Figure 3.3

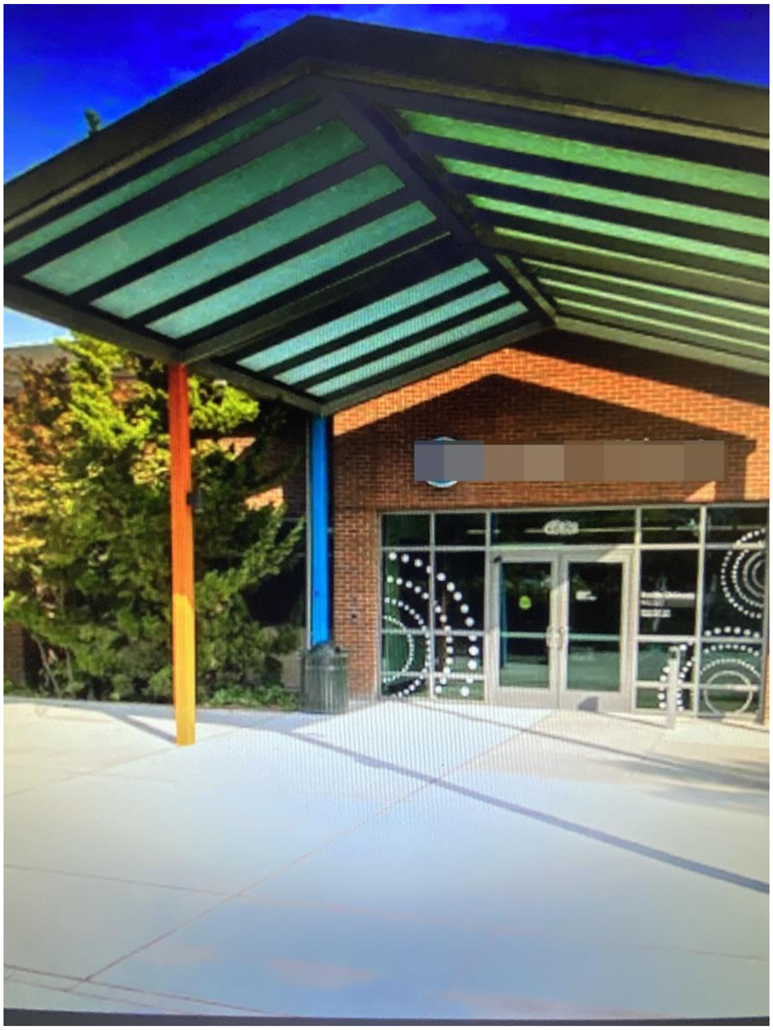
Ph: [redacted]
Fax: [redacted]
[redacted]

هذه معلومات دكتورة [redacted]

Participant's 10 parent: *"I chose it because this doctor really helped P10 during this stage. She always, if there was any problem … or any barrier… she always plans with us- me, P10… she always meets with us and solves P10's issues and problems ... I am very grateful to her during this stage. P10 really loves her and does not want to see another doctor except her."*

2. <u>Supportive Healthcare Facilities and Clinics:</u> Many families shared that having access to supportive clinics and facilities was integral during their children's HCT process. These clinics met their healthcare needs, were responsive, and were flexible. One parent shared Figure 3.4 narrating:

Figure 3.4


[redacted]

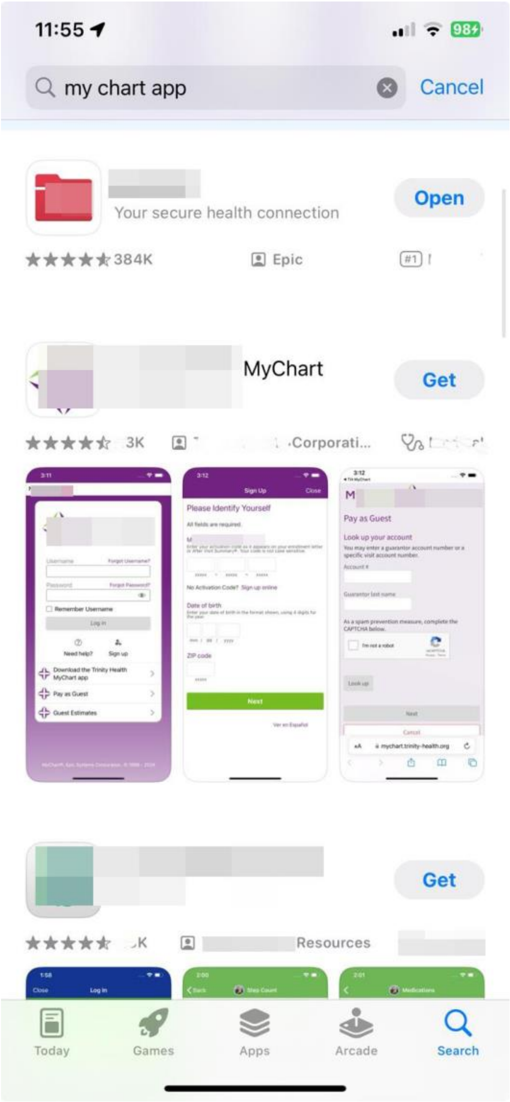
Participant's 7 parent: *"So they're meeting our needs… if you are like noticing side effects and they're very responsive… whenever I have a complain[t], and I ask for referral to a different specialty, they're very open in doing that."*

Figure 3.5

Participant's 4 parent shared Figure 3.5 saying*: "It's the same facility …. my experience with my son with this adult provider, and she welcomes participant's 4… [it is a] very much supportive clinic.*"

Another parent shared that her clinic's patient portal app helped her to easily communicate her child's needs on a timely manner with the healthcare team. She commented on Figure 3.6 saying:

Figure 3.6



Participant's 8 parent: *"I advise all the families contact the clinic and get the online app ... with MyChart, because MyChart has everything ... So whatever you want to deliver to your provider, just send in a message.....it's the easy way and written document... So this is the best way to contact your healthcare provider."*

3. <u>Independence and Personal Growth:</u> Several families highlighted the importance of youth independence during HCT through decision making, skills development, education, and physical activity involvement. One parent highlighted this by sharing her surprise about

her child’s tolerance to undergo a medical procedure (MRI scan) that he used to be scared of Figure 3.7:

Figure 3.7

Participant’s 8 parent: *“This photo means a lot for me. After the last seizure … the doctor refer me to the MRI and I'm so scared in the beginning; Participant 8 cannot accept somebody touching him and put him in this big machine…[it] is so scary for him … I'm really [didn’t] realize my son, he can do that. It is like a big challenge for him... So when he go[es] there and [is] laying down, it's really surprising me. So I'm just feeling in that moment how is he growing up and understanding what's going on around him and he's really patient…I feel he's growing up… he understands, he's more calm and … transitions maybe to the adult instead of being as a child. So I'm almost crying in this moment.”*

Another parent shared a picture of her son's current school Figure 3.8 emphasizing the importance of acquiring independence skills saying: *" This school is teaching him how to shop by himself and pay money... they teach him to be independent."* (Participant's 13 parent)

Figure 3.8

4. <u>Providers' Cultural Competence:</u> Middle Eastern cultural competence was important for many families who expressed their preference for providers who are sensitive to their cultural needs or share similar cultural backgrounds. Families shared that this alignment would facilitate communicating their needs, particularly sensitive topics. For example, one parent shared Figure 3.9 explaining:

Figure 3.9

Participant's 7 parent: *"So I think I if we were able to have such a provider [same background], we won't fear being judged to share some opinions … Participant 7 has some questions about puberty … but it's always a challenge to know what topics to talk about openly… the provider was talking to him… you can do that if you have permission, but we have a different opinion about that. It's not only about permission, it's about what's right and what's wrong in our culture."*

Participant 12's parent shared how their provider's experience with diverse cultural communities had positively influenced their interactions, noting: *"Everybody comes from a background, she has [a] different background, but she also has knowledge and experience to deal with the kind of people like us and others. She works a lot with the.. I think, with the immigrant … she's respectful, helpful, she always like friendly, and participant 12 loves her."*

The main HCT barriers were also summarized into four key subthemes. These are: health insurance coverage issues, lack of HCT planning, preparation, and resources, Independence and readiness challenges, gender specific provider preferences. Each theme is outlined next with the supporting participants' quotes.

1) Health Insurance Coverage Issues: Most families shared that they faced health insurance coverage issues with the current public insurance plans that led to challenges in accessing needed medications, vitamins, therapies, and optical aids. For example, participant 12's parent articulated her frustration on how her child's insurance would not cover critically prescribed ophthalmic lenses saying: "*The problem is that his insurance doesn't cover the lenses, and we had to pay out of pocket.*" When sharing Figure 3.10.

Figure 3.10

Participant's 13 parent faced similar challenges in securing insurance coverage for her child's vitamins and medications to manage his brittle bone condition, often having to cover these expenses themself while sharing Figure 3.11:

Figure 3.11

Participant 13 parent: " *Because he has osteoporosis, for example vitamins and medicines that he must take to promote his bone health. If insurance does not cover for these I have to buy them for him. What should I do these are essential for him."*

Additionally, several families shared that they had long wait times, that sometimes became years of waiting, to get care in specialized care clinics such as those who perform applied behavior analysis, as this parent narrated Figure 3.12:

Figure 3.12

Participant's 7 parent: *"When it comes to applied behavioral analysis, the ABA especially in his age group … So his insurance, which is [public insurance A] … maybe 6 companies that provide ABA services for his age group. We've been on the waiting list since 2021. He's not, he's not getting any ABA for the past 3 years … the case manager … she explicitly told me you need to try getting him a private insurance."*

2) Lack of HCT planning, preparation, and resources*:* Many families shared that they lacked a clear understanding of what HCT is, in relation to its timeline, steps, and expectations. Many parents expressed uncertainty about when and how the transition from pediatric to adult healthcare would occur. For example, participant's 1 parent shared Figure 3.13 to represent her feeling of being trapped in the darkness during this phase:

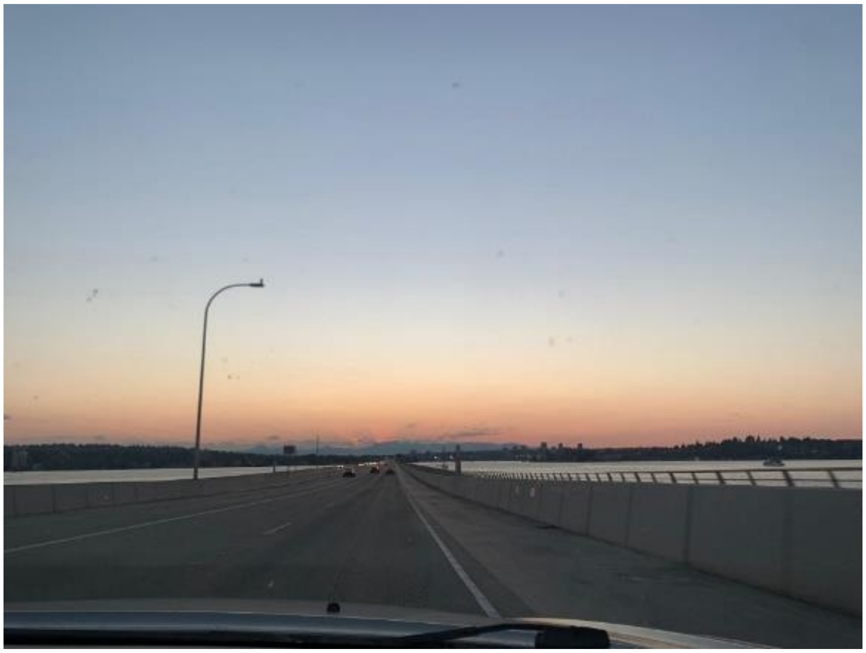
Figure 3.13

[redacted]

Participant's 1 parent: *"You know, she moved into this new phase [HCT phase] that is unknown to us, and I do not know what will happen to her."*

Most of these families shared that there was no or limited HCT resource sharing and guidance both in terms of the HCT information provided by providers and services available. This was evident in Participant's 13 parent experience who expressed her frustration by stating: *"They just said that Participant 13 needs to move from pediatrics into adult care, but no one told me where to go and what to do."* She metaphorically described their HCT experience as a long difficult trip while sharing Figure 3.14:

Figure 3.14



Participant's 13 parent: "*Yeah [it was a challenging HCT process], for a long time, for six months at least [we searched for an adult provider]!…No one explained to me what this phase is... It took me months of searching to find an adult clinic that accepts his insurance and I had to pay out of pocket because he was in severe pain.*"

3) Independence and readiness to lead challenges: Several families shared that they had concerns about their children's readiness to participate and actively lead their own care, such as making appointments or managing medicine by themselves, which complicated their HCT process. Also, many families shared their perceptions that their child lacked awareness of their healthcare needs and struggled to communicate effectively with providers. For instance, participant's 2 parent expressed her concern about her son's ability to express his needs, sharing that she often had to speak for him in medical settings commenting on Figure 3.15:

Figure 3.15

Participant’s 2 parent: *“Youth with disabilities sometimes don’t know what is going on around them, so we [caregivers] have to communicate their needs.”*

Additionally, some participants reported challenges related to medication management and behavioral issues, such as participant’s 7 parent, who highlighted the difficulties in managing her son’s medications as he transitioned into adulthood, narrating Figure 3.16:

Figure 3.16

Participant's 7 parent: *"I shared the photo of a new medication that he started…it wasn't an easy change of medication … so he had experienced a lot of mood disturbances… I feel him like hitting this transitional area between adulthood and teens had a lot of issues."*

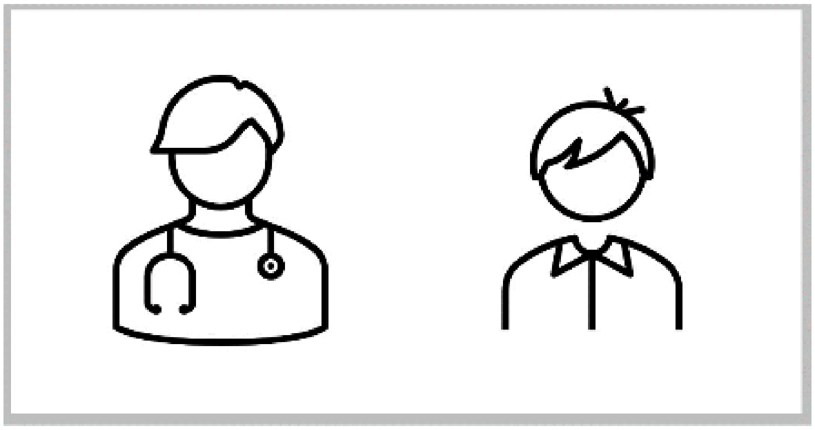
Figure 3.17

Participant’s 10 parent shared proudly this graduation photo of her daughter offering deeper insight about her disability perspective as shown in Figure 3.17 : *" This [adulthood transition} was really hard on her because her mind is still childlike and not mature enough. It was really hard on her to study and search for a job at the same time. It was hard but she did it and we were very happy that she [got] over this!"*

4) <u>Gender Specific Provider Preferences:</u> Many families shared that they prefer same-gender providers to take care of their children’s needs especially when sharing personal and sensitive topics. These families expressed their preference of talking to healthcare providers of the same gender as them or their child due to cultural norms, yet often they

struggled to find such providers. Participant's 6 parent shared her struggle and hesitation in sharing certain health related topics with her son's female provider narrating Figure 3.18:

Figure 3.18



Participant's 6 parent: *"I cannot share private things with the current provider because he needs a male doctor."*

3.5 Discussion

The resulting themes highlighted the main factors impacting HCT from the perspectives of the Middle Eastern youth and their families. Facilitators included having supportive healthcare providers and facilities, independence, personal growth, and providers' cultural competence. Barriers included health insurance coverage issues, lack of HCT planning, preparation, and resources, independence and readiness to lead challenges, and gender-specific preferences. Participants' perspectives were visually supported by the shared impactful photos and stories that further enriched the contextual and cultural understanding (Williamson et al., 2020) of the experiences of Middle Eastern YIDD and their families during HCT.

Themes describing HCT facilitators align with the broader literature about HCT. Many studies have consistently highlighted the integral role of having effective communication and interpersonal relationships between patients and healthcare providers to enhance the HCT experience. For example, studies showed that having a strong support system from healthcare providers significantly contributes to a smoother transition process for youth with chronic health conditions (Betz et al., 2013; Hobart & Phan, 2019). Also, these findings support the previous literature that stresses the need for patient-centered HCT programs (Hobart & Phan, 2019) and the finding that YIDD and their families seek proactive healthcare providers who address their specific needs (Betz et al., 2013). Moreover, having culturally sensitive healthcare providers emerged as one of the main themes for these families' HCT factors. This theme echoes the reported emphasis that cultural mismatch could adversely impact the quality of care during HCT (Hobart & Phan, 2019).

The independence and personal growth subtheme mirrors the previous literature about the significance of self-efficacy during HCT for YIDD. A systematic review identified self-efficacy as a key HCT facilitator, defined as the belief in one's ability to manage and overcome the challenges faced during HCT from pediatric to adult healthcare. Self-efficacy is crucial in forming how YIDD advocate for themselves and manage their healthcare needs during this critical phase. This review emphasized that fostering self-efficacy among young adults with cerebral palsy empowers them to engage actively in their care and communicate effectively with providers (Mitchell et al., 2023). While self-efficacy does not fully reflect independence and personal growth, it forms an integral part of both.

Most of the themes related to HCT barriers align with the available literature on HCT in other populations. The health insurance coverage theme was reported as a significant barrier in a systematic review on HCT for youth with chronic illness (Gray et al., 2018). Similarly, independence struggle and feeling of being unprepared for managing self-care needs among youth during the HCT phase was discussed in this same systematic review (Gray et al., 2018). The lack of HCT planning, preparation, and resource subtheme in this study resonates with the results shared by other studies that parents felt unprepared for the future with uncertainty and unmet needs (Betz et al., 2015; Gray et al., 2018).

Additionally, the gender-specific preference subtheme reveals discomfort in sharing certain healthcare needs with care providers who are not from the same gender as youth. This might be explained by the fact that the Middle Eastern cultural norms and expectations favors gender segregation, which might lead to this preference of same gender interactions (Abo-Zena, 2019). This finding supports the notion that gender related dynamics could create discomfort and impede patient-provider communication during HCT for youth with chronic illness in cultures that have strong gender norms (Gray et al., 2018), such as the Middle Eastern culture. This barrier emphasizes the need for culturally sensitive and competent healthcare providers to meet the unique needs of this population during the HCT phase. Moreover, many of the shared photos and quotes provided insight into Middle Eastern parental views of disability. These views commonly align with the Middle Eastern cultural norms of viewing disability as a problem and framing it in the “normal” versus “abnormal” binary of being (Mohamed Madi et al., 2019). This suggests that parental views conceptualizing and understanding disability are aligned with the medical/deficit model perspective, which problematizes and individualizes disability (Davis & Museus, 2019). This perspective might be explained by the Middle Eastern cultural norms and beliefs about disability.

On the other hand, some of the reported systematic barriers such as healthcare providers' readiness (Gray et al., 2018) and limited accessibility to specialty clinics (Mitchell et al., 2023) were not identified as the main barriers by this study's participants. This might be explained by the geography of the sample in a large, well-resourced city, unique Middle Eastern cultural background and needs, or possibly by the fact that participants were already well connected to community resources for immigrants and refugees of color through ODMF.

Interestingly, English language deficiency did not emerge as a major challenge for these participants during HCT. This may be attributed to the availability of interpreters in Washington’s healthcare systems and having a family member who is fluent in English. Furthermore, this study’s participants did not report experiencing discrimination or stigma during their HCT process, which suggests a potentially unique context for this population. Other literature points to prevalent social stigma prevalent which impacted children with developmental disabilities and their families in some countries in the Middle East (Ciftci et al., 2013; Crabtree, 2007; Sulaimani & Mursi, 2022).

This study is unique because it is the first to explore the needs of Middle Eastern YIDD in the US, a group that is commonly understudied in healthcare research (Minority Rights Group International, n.d.). Additionally, this research study contributes significantly to the body of literature on HCT by elucidating factors that influence HCT experiences among Middle Eastern YIDD in the US. The application of photovoice narrative methodology was also unique in the HCT field and with this patient population in particular, establishing a novel approach that may benefit and empower families in this population. Moreover, the use of the photovoice method provided a compelling visual narrative aspect with rich insight into these participants’ lived experiences, that complements existing HCT research by revealing new aspects of HCT experiences (Macdonald et al., 2022; Madrigal et al., 2014; Walton et al., 2012; Wass & Safari, 2020). Interestingly, some participants chose to share screenshots and graphics rather than images of their family life. This might be explained by the participants' need to maintain privacy and confidentiality; these are highly valued in the Middle Eastern culture (Abokhodair & Vieweg, 2016). However, rather than a weakness, these results also highlight the agency and empowerment enabled by this technique; participants decide what and how to photograph to express their thoughts and experiences (Budig et al., 2018). This provides novel insights about the use of photovoice narrative method with this community.

These findings reflect the complexity of the HCT process, outlined in the HCT model that has been developed by the Healthcare Transition Research Consortium (Betz et al., 2014). This study examined the perspectives of Middle Eastern YIDD and their families on parts of this model's contextual factors mainly the healthcare system, family/social support, and individual domains. Additionally, adults' competencies measured by the independence level emerged as a main HCT factor in this study based on the families' perspectives, which supports its importance in the HCT process. This study shows how these personal, healthcare systems, family/social support, and individual domains interact together to shape the HCT experiences of those Middle Eastern YIDD and underscores the need for supportive and culturally sensitive HCT interventions to improve their experiences.

3.6 **Limitations**

This study had many limitations including a small sample size specifically representing a small number of Middle Eastern participants' country of origin, which restricts the generalizability of the findings. Further, this sample might not capture the full breadth and diversity of experiences within the targeted community in the US. Future studies need to explore the experiences of Middle Eastern YIDD during HCT in diverse geographical locations and healthcare systems. Second, the photovoice narratives in this study's findings are context and population-specific, which means that these results may not be transferrable to other populations and settings. However, because there is a significant lack of perspectives of Middle Eastern youth and caregivers who are immigrants and refugees in research, the study is one of the first to shed light on HCT experiences in this underserved population using this technique, which far outweighs potential limitations. Finally, the potential for bias through the involvement of the researcher as their perspectives and relationships might impact data collection and interpretation. This was mitigated by the researcher by maintaining a reflexivity journal throughout the study and the use of unconditional positive regard (Farber et al., 2018). In this journal, the researcher documented her thoughts and feelings during the research process allowing for ongoing self-reflection examination of how her assumptions might affect the research outcomes.

3.7 **Conclusion**

This study describes the visually documented experiences of Middle Eastern YIDD and their families during HCT in Washington State, revealing many facilitators and barriers. The primary reported facilitators were having supportive healthcare providers and clinics, cultural competence, and independence. The reported HCT barriers included health insurance coverage issues; lack of HCT planning, preparation, and resources; struggles with independence; and gender-specific preferences. Interestingly, English language deficiency did not emerge as a main barrier in this participants' sample. This might be explained by the availability of interpreters in the healthcare systems in Washington State. This study is novel in utilizing photovoice methodology to explore the unique needs of this minority group in the US, providing valuable insights about their experiences during HCT and their distinct cultural needs. Despite its limitations, this study lays the foundation for better understanding of the experiences of Middle Eastern YIDD during their HCT in the US.

3.8 Bibliography

Abokhodair, N., & Vieweg, S. (2016). Privacy & social media in the context of the Arab Gulf. Proceedings of the 2016 ACM Conference on Designing Interactive Systems, 672–683.

Aboul-Enein, B. H., & Aboul-Enein, F. H. (2010). The cultural gap delivering health care services to Arab American populations in the United States. Journal of Cultural Diversity, 17(1).

Abo-Zena, M. M. (2019). Being young, Muslim, and female: Youth perspectives on the intersection of religious and gender identities. Journal of Research on Adolescence, 29(2), 308–320.

Abudiab, S., de Acosta, D., Shafaq, S., Yun, K., Thomas, C., Fredkove, W., Garcia, Y., Hoffman, S. J., Karim, S., Mann, E., Yu, K., Smith, M. K., Coker, T., & Dawson-Hahn, E. (2023). "Beyond just the four walls of the clinic": The roles of health systems caring for refugee, immigrant and migrant communities in the United States. Frontiers in Public Health, 11. https://doi.org/10.3389/fpubh.2023.1078980

Anderson, K., Elder-Robinson, E., Howard, K., & Garvey, G. (2023). A systematic methods review of Photovoice research with indigenous young people. International Journal of Qualitative Methods, 22, 16094069231172076.

Balcazar, F., Keys, C., & Kaplan, D. (2006). Participatory Action Research and People with Disabilities: Principles and Challenges. Canadian Journal of Rehabilitation, 12.

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. Journal of Epidemiology and Community Health, 60(10), 854.

Betz, C. L. (2023). Health care transition planning for adolescents and emerging adults with intellectual disabilities and developmental disabilities: Distinctions and challenges. Journal for Specialists in Pediatric Nursing, 28(3), e12415.

Betz, C. L., Coyne, I., & Hudson, S. M. (2021). Health care transition: The struggle to define itself. Comprehensive Child and Adolescent Nursing, 1–15.

Betz, C. L., Ferris, M. E., Woodward, J. F., Okumura, M. J., Jan, S., & Wood, D. L. (2014). The health care transition research consortium health care transition model: a framework for research and practice. Journal of Pediatric Rehabilitation Medicine, 7(1), 3–15.

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. Nursing Outlook, 61(5), 311–336.

Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. Journal of Family Nursing, 21(3), 362–412.

Betz, C. L., O'Kane, L. S., Nehring, W. M., & Lobo, M. L. (2016). Systematic review: Health care transition practice service models. Nursing Outlook, 64(3), 229–243.

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: a tool to enhance trustworthiness or merely a nod to validation? Qualitative Health Research, 26(13), 1802–1811.

Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. Journal of Autism and Developmental Disorders, 47, 3380–3391.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.

Brown, M., Macarthur, J., Higgins, A., & Chouliara, Z. (2019). Transitions from child to adult health care for young people with intellectual disabilities: A systematic review. Journal of Advanced Nursing, 75(11), 2418–2434.

Budig, K., Diez, J., Conde, P., Sastre, M., Hernán, M., & Franco, M. (2018). Photovoice and empowerment: evaluating the transformative potential of a participatory action research project. BMC Public Health, 18(1), 432. https://doi.org/10.1186/s12889-018-5335-7

Burke, J. (2012). 'Some kids climb up; some kids climb down': culturally constructed play-worlds of children with impairments. Disability & Society, 27(7), 965–981.

Cahill, C. (2007). Doing research with young people: Participatory research and the rituals of collective work. Children's Geographies, 5(3), 297–312.

Castañeda, H., Holmes, S. M., Madrigal, D. S., Young, M.-E. D., Beyeler, N., & Quesada, J. (2015). Immigration as a social determinant of health. Annual Review of Public Health, 36, 375–392.

Chinn, D., & Balota, B. (2023). A systematic review of photovoice research methods with people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities.

Ciftci, A., Jones, N., & Corrigan, P. W. (2013). Mental health stigma in the Muslim community. Journal of Muslim Mental Health, 7(1).

Crabtree, S. A. (2007). Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. Disability & Society, 22(1), 49–62.

Davis, L. P., & Museus, S. D. (2019). What Is Deficit Thinking? An Analysis of Conceptualizations of Deficit Thinking and Implications for Scholarly Research. NCID Currents, 1(1). https://doi.org/10.3998/currents.17387731.0001.110

De Abreu Lourenço, R., Devlin, N., Howard, K., Ong, J. J., Ratcliffe, J., Watson, J., Willing, E., & Huynh, E. (2021). Giving a voice to marginalised groups for health care decision making. The Patient-Patient-Centered Outcomes Research, 14(1), 5–10.

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. International Journal of Qualitative Methods, 8(1), 54–63.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. Journal of Advanced Nursing, 62(1), 107–115.

Eneriz-Wiemer, M., Sanders, L. M., Barr, D. A., & Mendoza, F. S. (2014). Parental limited English proficiency and health outcomes for children with special health care needs: a systematic review. Academic Pediatrics, 14(2), 128–136.

Ezenkwele, U. A., & Roodsari, G. S. (2013). Cultural competencies in emergency medicine: caring for Muslim-American patients from the Middle East. The Journal of Emergency Medicine, 45(2), 168–174.

Farber, B. A., Suzuki, J. Y., & Lynch, D. A. (2018). Positive regard and psychotherapy outcome: A meta-analytic review. Psychotherapy, 55(4), 411–423. https://doi.org/10.1037/pst0000171

Grant, J., Nelson, G., & Mitchell, T. (2008). Negotiating the challenges of participatory action research: Relationships, power, participation, change and credibility. Handbook of Action Research, 589–607.

Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from pediatric to adult care: a systematic review. Journal of Pediatric Psychology, 43(5), 488–502.

Guralnick, M. J. (2007). The system of early intervention for children with developmental disabilities: Current status and challenges for the future. Handbook of Intellectual and Developmental Disabilities, 465–480.

Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. Intellectual and Developmental Disabilities, 51(5), 349–359.

Hobart, C. B., & Phan, H. (2019). Pediatric-to-adult healthcare transitions: current challenges and recommended practices. American Journal of Health-System Pharmacy, 76(19), 1544–1554.

Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. Intellectual and Developmental Disabilities, 46(1), 1–11.

Kaehne, A., Kiernan, J., & Ridley, J. (2019). Systematic review of study designs and methods in health transition research for young people with intellectual disabilities. Heliyon, 5(11), e02750.

Kester, J., Flanagan, M. F., & Stella, J. (2021). Transition Discoveries: Participatory Action Research to Design Pathways to Success. Career Development and Transition for Exceptional Individuals, 45(1), 31–43. https://doi.org/10.1177/21651434211026165

Kindon, S., Pain, R., & Kesby, M. (2007). Participatory action research: Origins, approaches and methods. In Participatory action research approaches and methods (pp. 35–44). Routledge.

Komaie, G., Gilbert, K. L., Arroyo, C., & Goodman, M. S. (2018). Photovoice as a Pedagogical Tool to Increase Research Literacy Among Community Members. Pedagogy in Health Promotion, 4(2), 108–114. https://doi.org/10.1177/2373379917715652

Lal, S., Jarus, T., & Suto, M. J. (2012). A scoping review of the Photovoice method: Implications for occupational therapy research. In Canadian Journal of Occupational Therapy (Vol. 79, Issue 3, pp. 181–190). https://doi.org/10.2182/cjot.2012.79.3.8

Lotstein, D. S., Kuo, A. A., Strickland, B., & Tait, F. (2010). The transition to adult health care for youth with special health care needs: do racial and ethnic disparities exist? Pediatrics, 126(Supplement_3), S129–S136.

Macdonald, D., Peacock, K., Dew, A., Fisher, K. R., & Boydell, K. M. (2022). Photovoice as a platform for empowerment of women with disability. SSM - Qualitative Research in Health, 2, 100052. https://doi.org/https://doi.org/10.1016/j.ssmqr.2022.100052

Madrigal, D., Salvatore, A., Casillas, G., Casillas, C., Vera, I., Eskenazi, B., & Minkler, M. (2014). Health in my community: Conducting and evaluating photovoice as a tool to promote environmental health and leadership among Latino/a youth. Progress in Community Health Partnerships: Research, Education, and Action, 8(3), 317.

Massachusetts, U. S. (2023). NVivo [Computer software] (14). QSR International.

Merriam, S. B., & Tisdell, E. J. (2015). Qualitative research: A guide to design and implementation. John Wiley & Sons.

Minority Rights Group International. (n.d.). Arab and other Middle Eastern Americans. Retrieved May 9, 2023, from https://minorityrights.org/minorities/arab-and-other-middle-eastern-americans/

Mitchell, D. L., Shlobin, N. A., Winterhalter, E., Lam, S. K., & Raskin, J. S. (2023). Gaps in transitional care to adulthood for patients with cerebral palsy: a systematic review. Child’s Nervous System, 39(11), 3083–3101.

Mohamed Madi, S., Mandy, A., & Aranda, K. (2019). The perception of disability among mothers living with a child with cerebral palsy in Saudi Arabia. Global Qualitative Nursing Research, 6, 2333393619844096.

Mohammed, M. (2022). Barriers to Healthcare Access for Refugees and Immigrants with Limited English Proficiency in Nebraska: A Systematic Review of the Literature.

Okumura, M. J., Saunders, M., & Rehm, R. S. (2015). The role of health advocacy in transitions from pediatric to adult care for children with special health care needs: bridging families, provider and community services. Journal of Pediatric Nursing, 30(5), 714–723.

Pain, R., Whitman, G., & Milledge, D. (2019). Participatory action research toolkit: An introduction to using PAR as an approach to learning, research and action.

Peel, K. L. (2020). A beginner's guide to applied educational research using thematic analysis. Practical Assessment, Research, and Evaluation, 25(1), 2.

Robards, F., Kang, M., Usherwood, T., & Sanci, L. (2018). How marginalized young people access, engage with, and navigate health-care systems in the digital age: systematic review. Journal of Adolescent Health, 62(4), 365–381.

Schmidt, A., Ilango, S. M., McManus, M. A., Rogers, K. K., & White, P. H. (2020). Outcomes of pediatric to adult health care transition interventions: an updated systematic review. Journal of Pediatric Nursing, 51, 92–107.

Sulaimani, M. F., & Mursi, N. B. (2022). Experiences of mothers in dealing with stigma related to their children with autism spectrum disorder in the Saudi context. Problems of Education in the 21st Century, 80(6), 851–864.

Suprapto, N., Sunarti, T., Wulandari, D., Hidayaatullaah, H. N., Adam, A. S., & Mubarok, H. (2020). A Systematic Review of Photovoice as Participatory Action Research Strategies. International Journal of Evaluation and Research in Education, 9(3), 675–683.

Sutton-Brown, C. A. (2014). Photovoice: A methodological guide. Photography and Culture, 7(2), 169–185.

Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., & Rotholtz, D. A. (2004). Support intensity scale. *Supports Intensity Scale Users Manual. Washington, DC: American Association on Mental Retardation*.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. Qualitative Inquiry, 16(10), 837–851.

Tyler Jr, C. V, & McDermott, M. (2021). Transitioning patients with developmental disabilities to adult care. The Journal of Family Practice, 70(6).

Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. Autism, 18(7), 815–826.

Walton, G., Schleien, S. J., Brake, L. R., Trovato, C., & Oakes, T. (2012). Photovoice: A collaborative methodology giving voice to underserved populations seeking community inclusion. Therapeutic Recreation Journal, 46(3), 168.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. Health Education & Behavior, 24(3), 369–387.

Wass, S., & Safari, M. C. (2020). Photovoice—Towards engaging and empowering people with intellectual disabilities in innovation. Life, 10(11), 272.

Williamson, H. J., Chico-Jarillo, T. M., Sasse, S., Rennie, L., Etcitty, J. R., Howe, C. L., Lee, M. S., & Armin, J. S. (2023). A scoping review of health research with racially/Ethnically minoritized adults with intellectual and developmental disabilities. Developmental Disabilities Network Journal, 3(2).

Williamson, H. J., van Heumen, L., & Schwartz, A. E. (2020). Photovoice with individuals with intellectual and/or developmental disabilities: Lessons learned from inclusive research efforts. Collaborations: A Journal of Community-Based Research and Practice, 3(1), 8.

Xu, Y., Zeng, W., Wang, Y., & Magaña, S. (2022). Barriers to Service Access for Immigrant Families of Children With Developmental Disabilities: A Scoping Review. Intellectual and Developmental Disabilities, 60(5), 382–404.

Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in diagnosis and treatment of autism in Latino and non-Latino white families. Pediatrics, 139(5).

Zuckerman, K. E., Mattox, K., Donelan, K., Batbayar, O., Baghaee, A., & Bethell, C. (2013). Pediatrician identification of Latino children at risk for autism spectrum disorder. Pediatrics, 132(3), 445–453.

Chapter 4. Introduction

This chapter has two main parts. Part one reports the health-related quality of life for Middle Eastern youth with intellectual and developmental disabilities (YIDD) during their healthcare transition (HCT) in a research article format. Part two presents the initial results from the development and evaluation of two HCT resources designed for Middle Eastern YIDD and families based on the cumulative data gathered for this project and outlined in Chapters 2, 3, and Part 1 of Chapter 4.

4.1 Part 1: Health-Related Quality of Life of Middle Eastern Youth with Disabilities during Healthcare Transition in Washington State

4.1.1 Abstract

Introduction: The current healthcare transition (HCT) literature has limited evidence about the healthcare access and health-related quality of life (HRQOL) of Middle Eastern youth with intellectual and developmental disabilities (YIDD) during this critical time. Considering this unique opportunity to engage with this community overtime, this study aimed to identify the current level of healthcare access and the HRQOL levels over a short time duration. **Methods:** Quantitative study design using short healthcare access survey and c the World Health Quality of Life – BREF (WHOQOL-BREF) measure were collected from 11 Middle Eastern YIDD (ages 14-24) and their caregivers residing in Washington State. The WHOQOL-BREF was collected twice over a mean interval of 2 (±1.8) months. Given the small sample size and lack of normality distribution, descriptive statistics and a Mann Whitney U test were done using R software to explore trends in data. **Results:** All participants reported having access to healthcare services. No statistical significance changes were detected between the initial and second assessments of the WHQOL-BREF raw scores. Over time, descriptive analysis of the WHOQOL-BREF domains showed slight improvements in the transformed scores of the physical and psychological domains with the highest improvement observed in the environmental domain. Furthermore, participants who were at the late HCT transition process (ages > 21 years) showed higher improvements in WHOQOL-BREF domains than those who were in the early HCT (ages < 21 years). **Conclusion:** This exploratory study provides initial insights into the healthcare access and HRQOL of Middle Eastern YIDD during their critical HCT phase. Despite these limitations and the missing social scores, this study provides preliminary evidence about healthcare access and HRQOL of this population during HCT in Washington State. Future research with a larger sample size is needed to better understand Middle Eastern YIDD experiences during HCT in the United States and to accurately evaluate HRQOL changes over a longer period of time.

4.1.2 Introduction

In the United States (US), individuals with intellectual and developmental disabilities face challenges when accessing the fragmented adult healthcare systems. Some of these challenges include communication issues, limited access to needed information, and physical inaccessibility, which often result in poor health outcomes (Alshammari et al., 2018; Bonardi et al., 2024). One particularly vulnerable group among this population is Youth with Intellectual and Developmental Disabilities (YIDD) who commonly report lower quality of life levels compared to their typically developing peers during the transition to adulthood (Blaskowitz et al., 2020), which emphasizes the need for a comprehensive lifelong care approaches for this vulnerable population (Videlefsky et al., 2019).

For Middle Eastern YIDD living in the US, the transition to adulthood presents unique challenges that may impact their Health-Related Quality of Life (HRQOL). This is mainly due to the interplay between Middle Eastern and US cultural differences, language barriers, and different healthcare needs (Abuelezam et al., 2018). The situation is further complicated for refugees and immigrant populations, who must navigate unfamiliar complex healthcare systems given the above challenges (Feinberg et al., 2020).

Healthcare transition (HCT), defined as the transfer process from pediatric to adult healthcare settings (Betz et al., 2021), is a challenging time for the YIDD and their families. In the US, a recent study found that YIDD have lower odds of receiving HCT services than to youth with other special needs (Casseus & Cheng, 2022). Furthermore, during HCT immigrant families of children with intellectual and developmental disabilities in the US encounter several access barriers that potentially impact their HRQOL and aggravate disparities (Xu et al., 2022).

HRQOL is a multifaceted construct that evaluates how the individual's health affects their capacity to lead a fulfilling life by utilizing multiple indicators (Bakas et al., 2012). These indicators represent the individuals' perception of their own functionality and health (Yin et al., 2016). This is a critical concept for evaluating the overall well-being of vulnerable populations such as the Middle Eastern YIDD. While the literature on HCT for YIDD is growing, there is a significant knowledge gap regarding the Middle Eastern population and their caregivers in the US. Addressing this gap is crucial, given the growing Middle Eastern population in the US and their unique cultural background which may play a vital role in shaping their HRQOL.

Examining the HRQOL of the Middle Eastern YIDD and their caregivers during HCT is crucial for several reasons. First, it can help to identify specific needs and potential interventions to improve the transition process. Second, this study can inform future culturally sensitive healthcare practices and policies. Lastly, this adds to the broader knowledge of how cultural background affects HRQOL and HCT experiences for YIDD and their families over time. This study aims to address this knowledge gap by:

- Identifying current healthcare access status of Middle Eastern caregivers' of YIDD in Washington State.
- Measuring and evaluating the HRQOL of the Middle Eastern YIDD in Washington State over time and during HCT process.

4.1.3 Methods

This study was approved by the institutional review board of the University of Washington (STUDY00019215). Informed consents and assents were obtained from all participants before study enrollment. Quantitative data were collected using a short healthcare access survey, and the World Health Organization Quality of Life (WHOQOL-BREF). These were done as part of an overarching study focused on HCT for Middle Eastern YIDD and their families (see Chapters 2 and 3).

4.1.3.1 Participants

Recruitment was conducted through collaboration with a non-profit organization named Open Doors for Multicultural Families, a local organization that serves diverse communities of individuals and families with intellectual and developmental disabilities. Flyers distributed via email, social media, and local organizations in Washington State. The inclusion criteria for youth participants were Middle Eastern immigrants or refugees residing in Washington State, aged 14-24 years, of any gender, with intellectual or developmental disability. Caregivers' inclusion criteria were: Age 18 or older, the legal guardian of Middle Eastern YIDD; primary caregiver of the YIDD, and lived in the same household as the Middle Eastern YIDD.

4.1.3.2 Data collection

A demographic data survey was conducted after participants' enrollment, and a short healthcare access survey was collected. Healthcare access was measured using this question for simplicity and clarity "Do you have regular healthcare visits with local provider currently?", replicating a previous study that used similar questions to investigate healthcare access (Coombs et al., 2021).

The WHOQOL-BREF is the short version of the WHOQOL-100, a validated measure that comprehensively evaluates the individual's HRQOL using four main domains: physical, psychological, social, and environmental. The scoring ranges from 0 to 100, higher scores indicate better quality of life (World Health Organization, 1996). This measure was chosen because it is a free tool with a valid Arabic version for Middle Eastern population (Almarabheh et al., 2023; Dalky et al., 2017; Ohaeri & Awadalla, 2009). In addition, it has high reliability and validity indices with a Cronbach's alpha coefficient of 0.70-0.91 and a test-retest window of 2 weeks (Almarabheh et al., 2023; Dalky et al., 2017). This measure was completed twice during the overarching study: the *first* was collected at enrollment (before Chapter 2 study) and the *second* was done after the completion of the photovoice narratives study (after chapter 3 study), with a mean interval time of 2 months (±1.8) between these two assessment points. The WHOQOL-BREF was completed by the Middle Eastern YIDD and their caregivers. Only three participants self-reported this measure, while the rest had their primary caregiver help them complete it as a proxy, with the same caregiver reporting at both assessment points. The researcher stressed the importance of YIDD agency by asking caregivers not impose their opinions and preferences when helping their child fill the measure and emphasizing that their role was only assisting and explaining the measure to the YIDD.

In light of this unique opportunity to engage with this community over short time frame (see chapters 2 and 3 for more details), the HRQOL measure was collected twice, at initial study enrollment and after the photovoice narratives interviews. This decision was made to collect baseline HRQOL data about this underserved population and to allow for capturing any potential changes in HRQOL over this period during the critical HCT process. This sampling approach provided valuable insight into the short-term dynamics related to HRQOL which might not be captured otherwise, while also identifying how HRQOL levels evolved with time.

4.1.3.3 Data analysis

Data were analyzed using R software (version 4.4.2, Boston, MA). Demographic information, healthcare access information, and the WHOQOL-BREF are presented below. The social relationships domain scores could not be calculated due to missing data of item 21 which asks participants to rate their sex life satisfaction. This decision was based on the WHOQOL-BREF manual recommendations (World Health Organization, 1996), however the raw data for the other WHOQOL-BREF domains were tested for statistical significance using Mann-Whitney U test to determine if any changes occurred over the study time period. The WHOQOL-BREF means for the initial and second scores were calculated for the available scores. Then, participants were classified based on their actual HCT, which is transferring out of the pediatric settings into before and after groups based on their age, WHOQOL-BREF was calculated for both of these.

4.1.4 Results

4.1.4.1 Demographic Data

Eleven participants completed the study procedures at both assessment time points. Participants' demographic information is displayed in Table 4. 1.

Table 4.1 Demographics and Clinical Characteristics of Youth Participants

Characteristic	N
Age, years	
Mean (SD)	18.2 (3.3)
Range	14 – 24
Gender	
Male	6
Female	5

Medical Diagnosis	
Cerebral Palsy	4
Down Syndrome	1
Autism	2
Autism with intellectual disability	2
Muscular Dystrophy	1
Osteogenesis Imperfecta	1
Reported Complexity of Needs Level*	
High	4
Moderate	5
Low	2
Country of Origin	
Iraq	9
Sudan	1
Syria	1
Educational level	
Associate degree	1
High School Diploma or GED	3
Some High School	5
Some Middle School	1
Some Elementary	1
Work Status	
Not Employed	10

Employed	1
Current Housing	
Living with parents	11
Communication Disability	
Yes	4
No	7
Primary Mode of Mobility	
Ambulant at home, school, and community	7
Wheelchair user at home, school, and community	4
Assistive Technology use	
None	5
Wheelchair	4
Communication Aid	4
Attend Specialty Clinics**	
Neurology	4
Orthopedic	2
Autism	2
Ophthalmologists	4
Rehabilitation	3
Transportation Mode	
Family Car	6

Hope link	2
Both	3

Note. N= 11. SD = Standard deviation. * Reported Complexity of Needs Levels: High = reporting functional limitations that require extensive level of support across several life domains, moderate = reporting functional limitations that require intermittent level of support in more than a few life domains, and low = reporting functional limitations that require minimal level of support in few life domains (Thompson et al., 2004). ** Some YIDD attended more than one specialty clinic.

4.2.1 Main Findings

All participants reported having regular healthcare visits to local health providers primarily using their families' cars. Table 4.2 includes the healthcare access data.

Table 4.2 Healthcare Access Data

Current Healthcare Services*	**N**
Primary Care Provider	9
Physical Therapy	4
Occupational Therapy	3
Speech and Language Pathology	3
Prosthetist & Orthotists	1
Behavior Therapy	3

Note. * Some YIDD had more than healthcare service.

Mann-Whitney U test for the raw scores of the WHOQOL-BREF resulted in p values > 0.05 for the scored domains of the first and second WHOQOL-BREF assessments (see Table

4.3). This indicates the lack of statistically significant differences in these results over time during the study period.

Table 4.3 Mann-Whitney U test Results

Domain	U-Statistic	P - Value
Physical Health	52.5	0.62
Psychological Health	52.5	0.62
Social Relationships	NA	NA
Environment	47.5	0.41
Overall QOL	39.0	0.14
General Health	59.0	0.94

Note. NA = Not Applicable.

The mean scores for WHOQOL-BREF are outlined in Table 4.4. Improvements were observed in all WHOHRQOL-BREF domains with the most notable improvement observed in the environmental domain, which reached the threshold for Minimal Clinical Important Difference for transformed scores. The mean social relationships raw scores of the two reported items at the initial and second assessments were (7.4 ± 2.2) and (7.5 ± 1.7) respectively.

Table 4.4 WHOQOL-BREF Results Over Time

Domain	Initial Assessment (SD)	Second Assessment (SD)
Physical Health	56.2 (22.8)	58.1 (23.7)
Psychological Health	60.2 (13.6)	62.9 (18.2)
Social relationships	NA	NA

Environment	59.9 (13.2)	67.3 (15.7)
Overall QOL	3.6 (0.8)	4.2 (0.8)
General Health	3.6 (0.9)	3.7 (0.9)

Note: Domain scores range from 0 to 100, except for the Overall QOL and General Health, which range from 1 to 5. Higher scores indicate a better quality of life. SD = Standard Deviation. NA = Not Applicable.

The participants were then classified into two groups by age to reflect their HCT process status: Early HCT (< 21 years old), and late HCT phase (> 21 years old). The Mann Whitney U test was done on the raw domains scores with no statistical significance detected (Table 4.5).

Table 4.5 Mann Whitney U test Results of WHOQOL-BREF Based on Participants Actual Transfer

WHOQOL-BREF Domains	**Before Actual Transfer (Ages < 21 years, N = 8)**		**After Actual Transfer (Ages ≥ 21 years, N = 3)**	
	U statistic	**P - value**	**U statistic**	**P - value**
Physical Health	31.5	0.96	4.0	0.7
Psychological Health	29.5	0.83	3.0	0.7
Social relationships	NA	NA	NA	NA
Environment	25.0	0.49	3.0	0.7
Overall QOL	22.2	0.27	3.5	0.7
General Health	32.0	0.96	4.5	1.0

Note: * N = Sample size. SD = Standard Deviation. NA = Not Applicable. QOL= Quality of Life.

The WHOQOL-BREF domains scores for each group are shown in Figures 4.1 and 4.2.

Figure 4.1

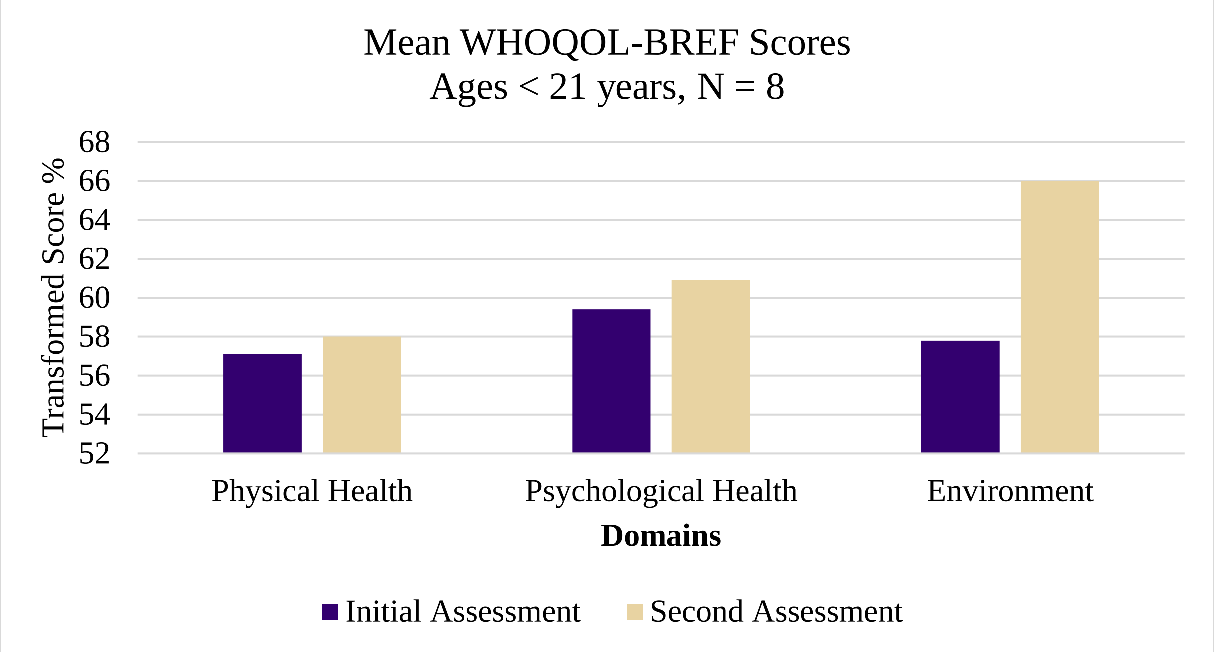
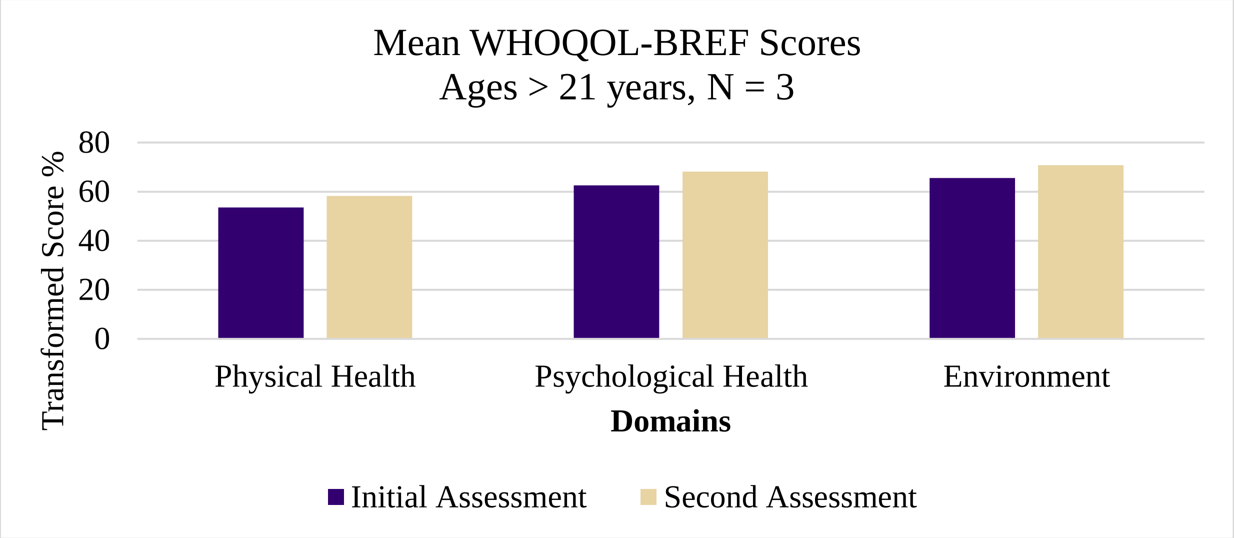


Figure 4.2



4.1.5 Discussion

The findings of this study show that all participants had access to healthcare through regular visits, and many had specialty clinic visits and a reliable means of transportation. However, this study view of healthcare access is just a snapshot, it is somewhat limited as it does not capture all aspects of the healthcare access such as service affordability, wait times, and cultural appropriateness of care (Gulzar, 1999).

Further, HRQOL remained relatively stable during the study period, with non-significant increases seen in most domains of the WHOQOL-BREF. Though no statistical differences were detected in raw scores, changes were observed in several transformed WHOQOL-BREF domain scores, and one domain reached Minimal Clinically Important Difference using the transformed scores (4.1-6.6) (Pietrzykowski et al., 2024). It is important to note that the missing social relationship item scores prevented scoring this domain. Notably, item 21 in the social relationships domain was not asked, and remained unanswered by all participants. This item asks about the participants' satisfaction with their sexual life, which many did not respond to because of the Middle Eastern cultural norms and beliefs that prohibit sexual activity before marriage (Bteich et al., 2017). Furthermore, the familiarity and understanding of the researcher with the Middle Eastern cultural norms and for trust building considerations the researcher did not ask for re-filling or reporting of this item, as this shows respect to the families' norms and traditions. Consequently, not all items in the social domain were scored.

Though this was not an intervention study, one possible explanation for the increase in scores over a relatively short study duration was that active participation in the research process that involved participatory methods (i.e. photovoice narratives, detailed in Chapter 3), may have enhanced self-reflection about overall HRQOL and HCT experiences (Walton et al., 2012; Wass & Safari, 2020). Additionally, the WHOQOL-BREF findings across various domains of the HCT process provide valuable insights into participants HRQOL. This suggests that there are notable improvements between early and late transfer in favor of the older group in both physical and psychological domains. In contrast, the younger group had a higher mean change in the environmental domain than did the older group. This might suggest that this group may have different physical and psychological needs that are met later in the HCT process, or that the uncertainty experienced by the younger group impacted these domains of their HRQOL. These aligns with the findings of a previous study that emphasized that the healthcare experiences of youth with chronic conditions with higher HCT readiness had better HRQOL compared to those with lower readiness and poorer healthcare experiences (Kallio et al., 2024).

4.1.5.1 Limitations

This study had several limitations. First the small sample size that does not fully reflect the whole Middle Eastern region and the Middle Eastern population in the US. Further, this study took place in Washington State which is a single geographic region in the US, which limits the interpretation and generalizability of the results. Third, for most participants the HRQOL measure was filled using proxy reporting, which limits the reliability of these data and might infuse caregivers' bias by under or over estimation of the YIDD HRQOL scores. Further, the incomplete social relationship domain scores were not measured due to missing items scores. Despite these limitations, the observed improvements in some of the WHOHRQOL-BREF warrant future examination and testing considering the unique challenges faced by this population.

4.1.5.2 Conclusion

This study is one of the first to describe the HRQOL of the Middle Eastern YIDD during the HCT process in the US. The results provide valuable insight into the current healthcare access status and the nature of the HRQOL for this population. Healthcare providers and policy makers need to consider these insights when developing support services and policies for this population. Future research with larger sample size and to expand this study's findings is needed to better understand the causes behind these differences during the HCT phase in Washington State.

4.1.6 Bibliography

Abuelezam, N. N., El-Sayed, A. M., & Galea, S. (2018). The health of Arab Americans in the United States: an updated comprehensive literature review. *Frontiers in Public Health*, *6*, 262.

Almarabheh, A., Salah, A. Ben, Alghamdi, M., Al Saleh, A., Elbarbary, A., Al Qashar, A., Alserdieh, F., Alahmed, F., Alhaddar, H., & Alsada, L. (2023). Validity and Reliability of the WHOQOL-BREF in the Measurement of the Quality of Life of Sickle Disease Patients in Bahrain. *Frontiers in Psychology*, *14*.

Alshammari, M., Doody, O., & Richardson, I. (2018). Barriers to the Access and use of Health Information by Individuals with Intellectual and Developmental Disability IDD: A Review of the Literature. *37*, 294–298. https://doi.org/10.1109/ichi.2018.00040

Bakas, T., McLennon, S. M., Carpenter, J. S., Buelow, J. M., Otte, J. L., Hanna, K. M., Ellett, M. L., Hadler, K. A., & Welch, J. L. (2012). Systematic review of health-related quality of life models. *Health and Quality of Life Outcomes*, *10*(1), 134. https://doi.org/10.1186/1477-7525-10-134

Betz, C. L., Coyne, I., & Hudson, S. M. (2021). Health care transition: The struggle to define itself. *Comprehensive Child and Adolescent Nursing*, 1–15.

Blaskowitz, M. G., Scott, P. W., Randall, L., Zelenko, M., Green, B. M., McGrady, E., Famularo, E., & Lonergan, M. (2020). Closing the gap: Identifying self-reported quality of life differences between youth with and without intellectual and developmental disabilities. *Inclusion*, *8*(3), 241–254.

Bonardi, A., Abend, S. L., & Ne'eman, A. (2024). Healthcare access and delivery for people with intellectual and developmental disability in the United States: Policy, payment, and practice considerations. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(2), e12487.

Bteich, G., Hajj, M., Accaoui, E., & El Abed, A. (2017). Sexual perception of young Lebanese students. *Health*, *9*(02), 299.

Casseus, M., & Cheng, J. (2022). Variations in healthcare transition preparation among youth with chronic conditions. *American Journal of Preventive Medicine*, *62*(5), e275–e283.

Coombs, N. C., Meriwether, W. E., Caringi, J., & Newcomer, S. R. (2021). Barriers to healthcare access among US adults with mental health challenges: A population-based study. *SSM-Population Health*, *15*, 100847.

Dalky, H. F., Meininger, J. C., & Al-Ali, N. M. (2017). The reliability and validity of the Arabic World Health Organization quality of life-BREF instrument among family caregivers of relatives with psychiatric illnesses in Jordan. *Journal of Nursing Research*, *25*(3), 224–230.

Feinberg, I., O'Connor, M. H., Owen-Smith, A., Ogrodnick, M. M., & Rothenberg, R. (2020). The relationship between refugee health status and language, literacy, and time spent in the United States. *HLRP: Health Literacy Research and Practice*, *4*(4), e230–e236.

Gulzar, L. (1999). Access to health care. *Image: The Journal of Nursing Scholarship*, *31*(1), 13–19.

Kallio, M. M., Tornivuori, A., Kolho, K.-L., Culnane, E., Loftus, H., Sawyer, S. M., & Kosola, S. (2024). Changes in health-related quality of life during transition to adult healthcare: an international prospective cohort study. *Archives of Disease in Childhood*.

Massachusetts, U. S. (2023). *NVivo [Computer software]* (14). QSR International.

Ohaeri, J. U., & Awadalla, A. W. (2009). The reliability and validity of the short version of the WHO Quality of Life Instrument in an Arab general population. *Annals of Saudi Medicine*, *29*(2), 98–104.

Organization, W. H. (1996). WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. World Health Organization.

Pietrzykowski, M. O., Vranceanu, A.-M., Macklin, E. A., & Mace, R. A. (2024). Minimal clinically important difference in the World Health Organization Quality of Life Brief (WHOQOL-BREF) for adults with neurofibromatosis. *Quality of Life Research*, *33*(5), 1233–1240.

Stewart, D. W., & Shamdasani, P. N. (2014). *Focus groups: Theory and practice* (Vol. 20). Sage publications.

Tahoun, M. M., Ismail, H. M., Fiidow, O. A., Ashmawy, R., Hammouda, E. A., Elbarazi, I., & Ghazy, R. M. (2023). Quality of life among the Arab population two years after COVID-19 pandemic. *BMC Public Health*, *23*(1), 1268. https://doi.org/10.1186/s12889-023-16171-z

Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., & Rotholtz, D. A. (2004). Support intensity scale. *Supports Intensity Scale Users Manual. Washington, DC: American Association on Mental Retardation*.

Videlefsky, A. S., Reznik, J. M., Nodvin, J. T., & Heiman, H. J. (2019). Addressing health disparities in adults with developmental disabilities. *Ethnicity & Disease*, *29*(Suppl 2), 355.

Walton, G., Schleien, S. J., Brake, L. R., Trovato, C., & Oakes, T. (2012). Photovoice: A collaborative methodology giving voice to underserved populations seeking community inclusion. *Therapeutic Recreation Journal*, *46*(3), 168.

Wass, S., & Safari, M. C. (2020). Photovoice—Towards engaging and empowering people with intellectual disabilities in innovation. *Life*, *10*(11), 272.

World Health Organization. (1996). WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. World Health Organization.

Xu, Y., Zeng, W., Wang, Y., & Magana, S. (2022). Barriers to service access for immigrant families of children with developmental disabilities: A scoping review. *Intellectual and Developmental Disabilities*, *60*(5), 382–404.

Yin, S., Njai, R., Barker, L., Siegel, P. Z., & Liao, Y. (2016). Summarizing health-related quality of life (HRQOL): development and testing of a one-factor model. *Population Health Metrics*, *14*, 1–9.

4.2 Part 2: Developing and Evaluating Healthcare Transitioning Resources for Middle Eastern Youth with Intellectual and Developmental Disabilities

4.2.1 Introduction

Part 2 of this chapter builds on the overarching goal of this thesis to work collaboratively with the Middle Eastern youth with intellectual disabilities and their families to translate knowledge and improve their healthcare transitioning (HCT) experiences in Washington State. This translational process included developing draft resource materials based on the experiences shared during data collection, followed by initial evaluation by community stakeholders.

4.2.2 HCT Resource Development

Chapter 2, which explored the experiences of Middle Eastern youth with intellectual and developmental disabilities (YIDD) and their caregivers' using semi-structured interviews, highlighted the importance of having supportive disability resources such as local community organizations, specialized care, free transportation, and disability supportive programs to facilitate their healthcare access. Several participants also shared their key concerns and priorities during HCT including continuity of care. This sub theme underscored their fears from the unknown HCT and their unfamiliarity of the HCT process. Moreover, in the fourth theme, key needs during HCT, several participants shared that they needed detailed information and knowledge about HCT process including its phases and end result from the pediatric care providers. This was evident in the communication is the priority sub themes of this chapter. Additionally, one of the shared hurdles to accessing care was communication struggle resulting from English language fluency issues and lack of familiarity with medical jargons. This informed the decision of creating both of these resources in Arabic language besides the English version.

All of this informed the decision to create an introductory informational brochure and video to describe HCT.

Chapter 3 used photovoice narratives to engage participants as co-researchers to explore HCT facilitators and barriers in pictures and words. From the perspectives of YIDD and their caregivers, support from healthcare providers and access to healthcare facilities were one of the resulting facilitators while the lack of HCT planning and resources was one of the identified barriers. This also informed the decision to briefly introduce the HCT process and list helpful links as a part of the developed draft resources.

The findings from Part 1 of chapter 4 about Health-Related Quality of Life (HRQOL) for YIDD during HCT supported the need for providing additional information and guidance during this critical lifetime. Even though evidence about HRQOL levels among this population is scarce, these participants had lower HRQOL levels compared to the normative data about the general Arabic population that was ranging around (70 out of 100) for all WHOQOL-BREF domains (Tahoun et al., 2023).

In light of these findings and building on the identified facilitators and addressing some of the shared barriers for HCT, two main resources were developed. These are:

1. **Resource 1:** A written HCT guide in the form of a brochure with helpful resources for families written in Arabic and English. The brochure includes a definition of HCT, and descriptions of HCT goals, stages, preparation for HCT, and helpful HCT links (see Appendixes A and B)
2. **Resource 2:** A video version of the HCT brochure was developed, based on many families' feedback that the written materials, especially those in English, are overwhelming and

unclear. The video similarly defined HCT, goals, key components, and how to prepare for HCT. This video was recorded in both Arabic and English languages (see Appendix C).

4.2.3 HCT Resource Evaluation by Middle Eastern Parents of Youth with Intellectual and Developmental Disabilities

4.2.3.1 Method

This study was conducted with the ethical guidelines approval from the Institutional Review Board (IRB) at the University of Washington (STUDY00021720). Once the resource materials were developed, focus groups were conducted to evaluate the initial drafts of the HCT resources for Middle Eastern youth with disabilities and their families. This process focused on areas of consensus and divergence in the participants' views. This methodology allowed for an in-depth exploration of parents' perspectives on these HCT resources. The interactive nature of this method facilitated rich discussions and allowed the participants to build on each other's ideas (Stewart & Shamdasani, 2014).

4.2.3.2 Data Collection

Both the brochure and video were shared with all the participants via email. At the beginning of the session, these resources were presented to participants. Then, participants were asked to write down their initial assessments before engaging in the group discussions.

A one-hour single focus group session was conducted. Seven open ended questions about participants' impressions, understanding, and suggestions regarding these two resources were used from a semi-structured interview guide shown in Table 4.6 To facilitate rich discussions and allow participants to build on each other's ideas, a focus group format was chosen rather than individual interviews (Stewart & Shamdasani, 2014). The focus group discussion questions explored participants' perception of the resources, visual appeal, effectiveness in explaining HCT concepts, and any suggestions for improvement based on their own transition experiences.

Table 4.6 Focus Group Discussion Questions

1. How well did the brochure /video explain the concept of healthcare transition? Were there any aspects that were unclear or confusing?
2. Was the language and used terminology easy to understand? And if not, which parts were challenging?
3. How visually engaging did you find the brochure and video? What aspects of these worked well or could be improved?
4. Think back to of your child's experience transitioning into the adult care settings, what did you need during that time?
5. If you could change or add one thing to improve the brochure or video, what would it be?
6. How likely would you be to recommend these materials to others, and why or why not?
7. What sections of both resources were helpful, and Why?

4.2.3.2.1 Participants

Participants were recruited through purposive sampling by contacting Middle Eastern families who previously participated in the semi-structured interviews and photovoice narratives parts of this thesis (Chapter 2 and Chapter 3). This group session was conducted via zoom and audio recording using a digital recorder, after granting permission from all participants. Confidentiality was assured and all identifying information were removed during data transcription.

4.2.3.3 Data Analysis

The audio recording was transcribed verbatim, then it was analyzed using inductive thematic analysis with NVivo qualitative analysis software (QSR International, 2023). The analysis process included initial coding, development of themes, and refinement. NVivo was used to organize codes and identify patterns.

4.2.3.4 Results

4.2.3.4.1 Demographics

Four parents participated in this focus group. The demographic data of the participants are presented in Table 4.7.

Table 4.7 Demographic Characteristics of Participants

Characteristic	**n**
Mean Age (SD), years	45.74 (4.3)
Gender	
Male	1
Female	3
Country of Origin	
Iraq	3
Sudan	1
Educational level	
Master's degree	1
Bachelor's degree	3
Occupation	

Case Manager	1
Teacher	1
Medical Doctor	1
Caregiver	1
Employment	
Not Employed	1
Full time employment	1
Part time employment	2
Annual Household Income (USD)	
25,000 - 49,999	3
50,000 - 74,999	1
Mean Number of People in the Household (SD)	4 (1)
Mean Number of People with Disability (SD)	1 (0.4)

Note. N = 4. SD = Standard deviation. USD = United States Dollars.

4.2.3.4.2 Main Findings

Three main themes emerged from this focus group discussion, these are: clarity of these resources and informativeness level, visual design and formatting suggestions, missing information that is important to parents. These are outlined in detail below.

1- Clarity of these resources and informativeness level: All participants shared that these resources were generally clear, easy to read, and informative. Participant 3 noted: *"For me, it's informative, it's clear and informative, they cover everything*". Participant 1 agreed, saying: "*I agree, the video was really informative*." Participant 4 added: *"I think for me it's readable, I love the picture, I love the photo, it makes sense, even the questions, it's very clear."*

2- Visual design and formatting suggestions: All participants provided feedback on the visual appearance and formatting of the two resources. For the video and the brochure, Participant 1 said: *"I may also suggest putting it in the form of a PowerPoint presentation where you can use visual aids to help people focus on like the main information. In addition to, you know, how people learn different[ly], so maybe some visuals will also help people to focus on the main points… you might need to add the resource links in the form of QR codes, so people can just scan it with their phone".* Participant 3 added*: "if you add subtitles with it, because maybe some people they love to read too… and if you will put contacts, clinics, links in your flyers, that will help a lot."* Participant 4 commented on the HCT stages part of the brochure saying that it was not clear to her why there is a discrepancy between the age ranges and the stages saying: "*You make it in four categories. But …the age format is five. Can you just change that a little bit to make it similar? … I think if we color code the timeline that you made, it will [more] directly reflect what you mean… maybe the font size needs to be changed. [Make] the most important thing bigger than the other [material]".* There was consensus on the choice of the brochure color scheme, and participants considered it aesthetically pleasing and were enthusiastic as it matched the University of Washington logo colors. Participant 3 commented: *" I love the photo, it makes sense, a lot even the colors you pick, it's very much 2 colors, it's related to the UW, I love it, both colors, it's good choice."*

3- <u>Missing information that is important to parents:</u> some participants highlighted issues about information to add, such as that in Washington State, parents lose access to their child's medical records when the child turns 13 years old. Participant 1 said: *"I did not know that at the age of 13 I will have limited access to his records, so suddenly on his 13th birthday all of [his records] were closed and it took me a long time to be able to regain access. I think that might be a good information to give the parents to be prepared…If you don't start talking about this by the age of 13, you will find yourself kicked out of his records, and it might take a while to be able to get back. So this is something that I experienced with my son, and I wish [it on] nobody, it was just a nightmare. I did not know that was going to happen*." Participant 2 stressed this issue saying: "*I had the same problem with my daughter, she just turned 13, and I was at the dermatologist, and I said, 'But I can't see her chart, I would like to see the comments from the doctor's office' and they said, 'Well, you will not have access to her chart, she's 13."*

4.2.3.5 Discussion

This focus group provided valuable insights and recommendations for improving these two HCT resources. In general, the participating parents found that these two resources were clear, informative, and valued the overall design and content. However, they have shared many areas for modifying these resources to enhance their quality, effectiveness, and accessibility.

Limitations include the small sample size of the focus group which only included parents' perspectives. Future evaluations of resources should include a larger sample size and other stakeholders such as YIDD and clinicians.

Strengths of this focus group is the diversity of the parental background that included a clinician, case manager, teacher, and caregiver. Moreover, the small sample size allowed a deeper exploration of parents' perspectives.

Future plans for the translation of this work include updating these resources based on participants' recommendations and collaborative feedback. The long-term goal of this work is to share family-friendly HCT resources that are simple and informative for Middle Eastern families and YIDD. The developed brochure and video will be shared with the community partner (ODMF) and the participating families via emails and hardcopies in the planned photo exhibition event that will be held at the ODMF in January 2025. These resources could contribute to enhancing the preparedness for HCT among Middle Eastern population in the United States.

4.2.3.6 Bibliography

QSR International. (2023). NVivo [Computer software] (14). QSR International.

Stewart, D. W., & Shamdasani, P. N. (2014). Focus groups: Theory and practice (Vol. 20). Sage publications.

Tahoun, M. M., Ismail, H. M., Fiidow, O. A., Ashmawy, R., Hammouda, E. A., Elbarazi, I., & Ghazy, R. M. (2023). Quality of life among the Arab population two years after COVID-19 pandemic. BMC Public Health, 23(1), 1268. https://doi.org/10.1186/s12889-023-16171-z

Chapter 5. Conclusion

5.1 Dissertation Summary

This dissertation focused on the experiences of Middle Eastern Youth with Intellectual and Developmental Disabilities (YIDD) and their families during their healthcare transitioning (HCT) to adult care services in Washington State. To explore these experiences a mixed methods approach was used utilizing qualitative semi-structured interviews, participatory action research (photovoice narratives), and quantitative health-related quality of life (HRQOL) assessment.

Considering the current literature, the findings of this dissertation suggest that implementing a culturally sensitive and comprehensive approach during HCT is needed to improve the experiences of this Middle Eastern population locally. Further, this dissertation embedded a local community partner (Open Doors for Multicultural Families (ODMF) in the research process which added valuable support and facilitated connection building during the research process. This emphasizes the important role of these organizations in connecting researchers to the targeted communities and bridging recruitment challenges.

Qualitative interviews and photovoice narrative method may be powerful tools to empower families and communicate their needs and challenges of this under-represented community in the United States. Despite the needed efforts to facilitate power dynamics shift between the researcher and participants, many participants enjoyed photovoice narratives aspect of this dissertation and demonstrated active engagement which highlight the feasibility of this method among Middle Eastern YIDD and their caregivers. Moreover, the preliminary HRQOL results of the Middle Eastern YIDD during the HCT process revealed that they had moderated HRQOL transformed scores across the physical health, psychological health, and environment domains, while simultaneously reporting regular access to local healthcare services. Interestingly, participants who were at the later phase of the HCT process exhibited higher HRQOL in their physical, psychological, and environmental health domains of HRQOL than those who were in the earlier HCT process.

5.2 Implication for research

These findings can inform both healthcare access and HCT policy development and training for health care providers to better serve this population. This dissertation underscores the importance of implementing comprehensive and culturally sensitive approach during HCT to enhance the experiences of the Middle Eastern YIDD. Partnering with a local community organization was instrumental in realizing community outreach efforts and building trust. Utilizing qualitative interviews and photovoice narratives empowered the YIDD and their caregivers to share their experiences and communicate their needs.

Future studies that explore HRQOL of Middle Eastern YIDD are still needed. The primary HRQOL results suggest that the Middle Eastern YIDD may face challenges in many HRQOL aspects including physical, psychological, and environmental domains during their transition to adult healthcare services. These findings highlight the need for further research on HRQOL and YIDD overall quality of life. Studies with larger sample sizes that reflect a more generalized representation across the United States (US) are also needed to gain better understanding of the Middle Eastern YIDD experiences and HRQOL changes during HCT. Future HRQOL research studies using longitudinal study design are needed to track HRQOL changes across HCT phases. Policymakers need to work on sustaining the reported facilitators and addressing the main shared barriers faced by this population during HCT.

One crucial aspect to address in future studies is collecting data about the length of time participants have been in the US. This information was not collected in this dissertation but might be essential in future research studies as it may play a significant role in how participants report their healthcare access and HCT experiences. Time spent in the US to date may impact the participants' familiarity with the US healthcare system, their English language proficiency, and the process of building social support networks in the community. Another important aspect for future work is to include engagement strategies to better involve the youth participants, as their input was limited in this dissertation. This can be done by utilizing communication facilitation techniques with YIDD to increase engagement, such as communication aids and/or assistive technology. Successful engagement will also include providing clear and explicit instructions for parents about the need to have direct input from the YIDD themselves to support their participation as much as possible. Future work could also involve conducting research procedures in social community-based settings such as schools or recreational programs after obtaining parental consent.

To summarize, this dissertation lays the foundation for broadening the available evidence that supports the Middle Eastern YIDD during the HCT in the United States. This is one of the first studies to investigate the experiences and perspectives of this underrepresented group during HCT, and thus offers a significant addition to existing literature and evidence to support this often marginalized population. It is critical that research continues to understand Middle Eastern YIDD and their caregivers' experiences and culture in the context of healthcare provision in the US.

Appendices:

Appendix A. The Healthcare Transitioning Brochure in English page 1

Healthcare Transitioning Guide

By *Reham Abuatiq*
PT, PhD Candidate
University of Washington
Email: rabuat@uw.edu

What is HealthCare Transitioning (HCT)?

- HCT is the process of transferring from pediatric healthcare setting into adult ones.[1]
- HCT aims to develop self-management skills among youth to effectively use health services.[2]

What can youth do to prepare for HCT? [2,3]

- **Start planning early:**
  - Start preparing by13 years of age.
  - Get involved in your care decisions.
- **Encourage independence:**
  - Youth should start asking questions during appointments.

HCT Stages [2,3]

Prepare → **Build Independence** → **Plan** → **Adult Client**

12-14 › 14 -18 › 16 -18 › 18 -21 › 18 - 26

Age (years)

Appendix A. The Healthcare Transitioning Brochure in English page 2

What can youth do?[2, 3]

- **Practice HCT skills:**
  - Learn how to schedule appointments.
  - Fill out medical forms.
  - Learn how to use online patient portals.
- **Know your medical history,** medications, allergies.
- **Explore health insurance options.**
- **Search for potential adult providers** and ask others for recommendations.

Helpful resources:

1. Got Transition®: A national HCT resource center that offers HCT tools and resources (in English).
2. Center for Transition to Adult Health Care for Youth with Disabilities: a virtual HCT center that helps adults with disabilities through training (in English).
3. Seattle Children's Hospital HCT guide and resources (in English).

Acknowledgments:
Thanks to the Middle Eastern families and youth with disabilities who shared their insights and photos.

Photos Credits:
All photographs in this brochure are used with explicit permissions from Middle Eastern youth and families.

References:

1. Betz CL. Health care transition planning for adolescents and emerging adults with intellectual disabilities and developmental disabilities: Distinctions and challenges. *Journal for Specialists in Pediatric Nursing*. 2023;28(3):e12415.
2. Got Transition. Six Core Elements of Health Care TransitionTM. Accessed November 5, 2024. https://www.gottransition.org/six-core-elements/
3. Berens J, Wozow C, Peacock C. Transition to adult care. *Physical Medicine and Rehabilitation Clinics*. 2020;31(1):159-170.

Appendix B. The Healthcare Transitioning Brochure in Arabic page 1

دليل مرحلة الانتقال في نظام الرعاية الصحية

رهام أبو عتيق
أخصائية علاج طبيعي، طالبة دكتوراه في
جامعة واشنطن
البريد الإلكتروني: rabuat@uw.edu

ما هو الانتقال في نظام الرعاية الصحية؟

- هو عملية الانتقال من بيئة الرعاية الصحية للأطفال إلى بيئة الرعاية الصحية للبالغين.[1]
- يهدف الى تطوير مهارات إدارة الصحة الذاتية لدى الشباب لاستخدام الخدمات الصحية بفاعلية.[2]

كيف يمكنني التجهيز للانتقال لرعاية البالغين في نظام الرعاية الصحية؟ [2,3]

- ❖ **ابدأ التخطيط مبكرًا:**
  - قم بتقديم مفهوم الانتقال في الرعاية الصحية في سن 13 عامًا تقريبًا.
  - عزز حس المسؤولية.
- ❖ **شجع على الاستقلالية:**
  - نمي مهارات الاستقلال الذاتي.
  - إطرح الأسئلة أثناء مواعيد الطبية.

مراحل الانتقال في الرعاية الصحية:

التحضير
بناء الاستقلالية
التخطيط
مريض بالغ

14 -12
18 - 14
18 -16
21- 18
26 - 18

العمر (بالسنوات)

Appendix B. The Healthcare Transitioning Brochure in Arabic page 2

يتبع...ماذا يجب أن أفعل؟ 2، 3

- ❖ **تدرب على مهارات الانتقال:**
  - تعلم كيفية جدولة مواعيدك الطبية.
  - تدرب على تعبئة نماذجك الطبية.
  - تعرف على تطبيقات المرضى الإلكترونية .
- ❖ **اعرف تاريخك الطبي:**
  - تشخيصك وأدويتك
  - أي حساسية لديك.
- ❖ **ابحث عن خيارات تأمين الصحي تناسبك.**
- ❖ **ابحث عن مقدمي رعاية صحية للبالغين ملائمين واسال الآخرين.**

مصادر مفيدة لمرحلة الانتقال في نظام الرعاية الصحية:

1. ®Got Transition : مركز موارد وطني لانتقال الرعايةَ الصحيةَ يهدف إلى تحسين مرحلةَ انتقال الرعايةَ الصحيةَ. يوفر أدوات وموارد بالإنجليزيةَ.
2. مركز الانتقال إلى الرعايةَ الصحيةَ للبالغين للشباب ذوي الإعاقات: هذا المركز يساعد البالغين من ذوي الإعاقات من خلال توفير التدريب والموارد بالإنجليزيةَ.
3. دليل وموارد انتقال الرعايةَ الصحيةَ من مستشفى الأطفال في سياتل (بالإنجليزيةَ).

شكر وتقدير:

نتوجه بالشكر إلى العائلات والشباب الشرق أوسطيين من ذوي التحديات الخاصة وعوائلهم الذين شاركونا أفكارهم وصورهم.

حقوق طبع و نشر الصور:

جميع الصورالمستخدمة في هذا المنشور تم استخدامها بإذن صريح من الشباب والعائلات الشرق أوسطيين

المراجع:

1. **Betz CL**. تخطيط انتقال الرعاية الصحية للمراهقين والبالغين الناشئين ذوي الإعاقات الذهنية والإعاقات النموية: التمييزات والتحديات. مجلة المتخصصين في تمريض الأطفال. 2023;28(3):e12415 .
2. **Got Transition** ®. العناصر الأساسية الستة لانتقال الرعاية الصحية. تم الوصول إليه في 5 نوفمبر 2024. https://www.gottransition.org/six-core-elements/
3. Berens J, Wozow C, Peacock C. الانتقال إلى الرعاية الصحية للبالغين. عيادات الطب الفيزيائي وإعادة التأهيل. 020;31(1):159-170.

Appendix C. The Healthcare Transitioning Videos Dropbox Links

- **The English HCT Video version link :**

  https://www.dropbox.com/scl/fi/74cyol7415fjorm1mto8j/English-HCT-Video_default.mp4?rlkey=aofdo2ws9ahuw29srn1qu2xqt&st=xt2viqek&dl=0

- **The Arabic HCT Video version link :**

  https://www.dropbox.com/scl/fi/mo6wdzwstd37bg28dqo5v/Arabic-HCT-Guide_default.mp4?rlkey=306xmdppe3cyz3uivie8es7n8&st=v0rsjli1&dl=0

Appendix D: Positionality Statement

In qualitative research, self-reflection and openness are significant parts of the process to build credibility and openness. In this statement I intend to reveal my personal experiences and background that might have formed my approach to this research.

My background as a Middle Eastern physical therapist, with extensive experience working with individuals with disabilities in Jordan, has greatly influenced my views on healthcare transitioning (HCT) for youth with intellectual and developmental disabilities (YIDD). My professional background has offered me insights into the challenges faced by YIDD and their families while navigating healthcare systems, especially during their shift to adult care systems. Additionally, having a family member with Cerebral Palsy has provided me with insight into some of these challenges. However, I understand and acknowledge that these experiences do not make me an insider to the specific situations of Middle Eastern YIDD in the United States. I am also mindful of those potential biases that originate from my own background.

As a Middle Eastern mother who has recently moved to the United States, I share the same cultural, linguistic, and religious background with the study participants. This facilitated conducting this research in their native language and overcame the potential barriers faced by this population. While this shared background facilitated building rapport and trust in a relatively short time, I remained cautious of my potential biases based on this perceived fact. I frequently reflected on how this shared cultural background might influence data collection and analysis.

I identify as a Muslim, middle-aged woman of color, non-disabled, mother of three sons, and a doctoral candidate at the rehabilitation sciences program. All these intersecting identities have shaped my worldview and research approach and are inseparable of my personality. I acknowledge that my status as a non-disabled researcher and I have no child with a disability may restrict my understanding of participants' lived experiences. But I hope that sharing the same cultural background with them could facilitate their willingness to share their experiences and stories. I also am cognizant of the potential power imbalances that may arise due to my role as a researcher and the perceived academic status and knowledge by others. To address this and throughout my research study, I stressed my position in this research as a learner and highlighted the value of their lived experiences. The use of photovoice narratives as a participatory action research method aimed to further reduce these power differentials and promote participants' agency. My main goal was to comprehend the needs of Middle Eastern YIDD and their families during HCT and to communicate these needs to those who are interested in serving this community in the United States. While adhering to ethical research practice, respecting participants' agency, and focusing on their empowerment, I frequently shared my research goals with all participants. During this research journey, I was committed to self-reflection using reflexivity journal to carefully evaluate my assumptions, prejudices on data collection, evaluation, and analysis. I regularly shared my thoughts with mentor to promote the reliability and validity of this research study.

Through this positionality statement, I seek to offer the reader some background information about me as a researcher and how I approached these data. I also aimed to acknowledge the complex relationship between my personal and professional experiences and this research.