

 **Challenges to Diabetes Self-Management in Emerging Adults with Type 1 Diabetes**



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Disclosure to Participants

- **Notice of Requirements For Successful Completion**
 - Please refer to learning goals and objectives
 - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours
- **Conflict of Interest (COI) and Financial Relationship Disclosures:**
 - Presenter: Neesha Ramchandani, PNP, CDE – No COI/Financial Relationship to disclose.
 - This study was supported by funds from Jonas Philanthropies and the Jacqueline Fawcett Nursing Science Award.
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Objectives

- At the conclusion of this session, attendees will be able to:
 1. Describe the challenges faced by emerging adults with type 1 diabetes (T1DM) in their diabetes self-management.
 2. Describe what emerging adults with T1DM desire as part of their clinical follow-up care.
 3. Identify three different subgroups of emerging adults with type 1 diabetes who may have differing perspectives about diabetes self-management.

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Background



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Introduction to the Problem

- **Diabetes: A growing problem** ¹⁻³
 - 3rd most common chronic illness of childhood ⁴
 - Insulin replacement by injection necessary for survival ⁵
 - 2001-2009: ↑ 23% prevalence in individuals <20 yrs old (US) ⁶
 - ↑ 3% annually in youth <14 yrs old (worldwide) ¹
 - Only 1/2 of US adults with diabetes in good glycemic control ⁷⁻¹⁰
 - Insufficient numbers of diabetes clinicians → difficulty accessing comprehensive diabetes care ^{11,12}



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Introduction to the Problem (contd.)

- **Emerging adults (18-30 yrs old) with type 1 diabetes (T1D) at especially high risk of suboptimal glycemic control** ¹³⁻¹⁷
 - No longer Pediatrics but not yet established with Adult services
 - Paucity of transition programs for youth with diabetes in the US
 - Great variation in programs that do exist
 - Competing life demands/multiple demands of emerging adulthood
 - Unstable living conditions
 - → lost to F/U
 - Usually do not keep up with complex diabetes regimen sufficiently well to maintain good glycemic control



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Developmental Issues & Emerging Adulthood (18-30 yrs old) 21,22

Definition (Arnett) 23

- Identity exploration
- Instability
- Self-focus
- Feeling in-between
- A time filled with optimism where anything seems possible



Developmental Transition Tasks 14,23

- Establishing independence
- Defining who they are
- Making important educational and/or vocational-career choices

Additional Developmental Challenges with T1D 14

- Physiological changes
- Decreased adherence to diabetes self-management (DSM) tasks
- Desire to appear "normal"

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Situational Transition Issues: Emerging Adults with T1D

<p>Challenges</p> <ul style="list-style-type: none"> • Changes in support systems • Living apart from one's parents • Irregular schedules • Different eating behaviors • Fear of hypoglycemia • The desire to be "normal" • (Refs 21, 24-28) 	<p>Consequences</p> <ul style="list-style-type: none"> • Effect on academics • Effect on job performance • Effect on DSM practices • Decreased frequency of diabetes follow-up visits • Ensuing deterioration in glycemic control • (Refs 11, 12, 24, 26-28, 39-43)
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Organizational Issues: Transition of Medical Care

- Great differences between pediatric and adult diabetes care services 10,12,44
- Adult diabetes services unprepared for emerging adults' developmental needs 10,12,44
- Very few effective transition programs in the U.S. 12,45
 - Inconsistent clinical findings 14
- ↓ # of visits after transition if no engagement 14,42,46-48
- Structure and consistency key 14,47,49-52




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Gaps in the Literature

- Limited intervention literature focused on access to care and successful transition
- **Unique developmental, social, and emotional challenges of emerging adulthood not sufficiently addressed**
- **Cultural diversity & differing needs throughout emerging adulthood generally not addressed**



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Purpose

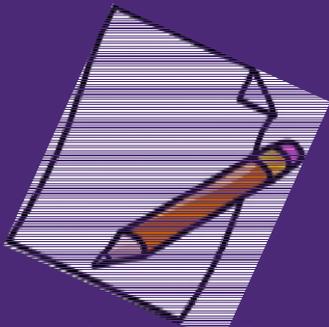
To explore developmental, situational, and organizational challenges experienced by a diverse group of emerging adults ages 18-29 years old with T1D (undergirded by Meleis' Transition Framework).
Their perspectives on creating a supplemental, developmentally-informed diabetes management program that will support navigation of diabetes self-management (DSM) in collaboration with their health care providers (HCPs) as they transition to adult care were also explored.



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Methods



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Methods

- **Design**
 - Qualitative descriptive study
 - Focus groups with supplemental interviews
- **Sample**
 - Purposive sample of emerging adults recruited from NYULMC pediatric & adult diabetes clinics and snowball/referral sampling
 - Stratified by gender, attempted to stratify by age

Inclusion Criteria	Exclusion Criteria
18-29 yrs old with T1D	Pregnant or breastfeeding
Internet access	Unstable renal or thyroid disease
English-speaking	On corticosteroid therapy
Able to function independently	Cancer actively being treated

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Methods (contd.)

Data Collection & Management

- **Focus groups**
 - 4 focus groups held:
 - 4 females, 19-25 years old
 - 3 females, 20-23 years old
 - 8 females, 22-29 years old
 - 3 males, 20-25 years old
 - 3 interviews held (19-21 year-old males)
 - Informed consent; Demographic & Clinical Data form
- **Focus Group Question Topics**
 - DSM practices
 - Facilitators and barriers to performing DSM tasks
 - Unmet needs in the participants' current healthcare services

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Methods (contd.)

Data Analysis

- Scientific adequacy of findings ensured with:
 - Peer debriefing
 - Employing reflexivity
 - Member checks
 - Audit trail
 - Rich descriptive data
 - Triangulation of data sources
- Informational redundancy reached except for the following:
 - Issues specific to Black females
 - Males

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Methods (contd.)

- **Data Analysis (contd.)**
 - Descriptive statistics: Microsoft Excel
 - Focus group qualitative data:
 - Krueger note-based method, with audio tape corroboration
 - Analyzed for themes using Meleis' Transition Framework as a guide
 - Also analyzed for themes regarding their perspectives and recommendations on what types of supportive services and/or resources they would be interested in using to help them navigate DSM during this time
 - Interviews analyzed for themes, collapsed into one group, then analyzed alongside the focus groups



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Methods (contd.)

- **Trustworthiness**
 - Credibility, transferability, dependability, and confirmability of the findings for qualitative data
 - Focus group field notes/transcripts reviewed by a second person for corroboration of identified themes and to ensure trustworthiness of the data
 - Member checking – all 4 who responded (3F, 1M) confirmed findings were accurate
- **Reflexivity**
 - Employed
 - 3 objective researchers read study transcripts to ensure transparency and objectivity



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Results



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Finding a Balance (contd.)

- Males: *"I'm pretty chill about everything. Kind of just roll with the punches and move on with my life."* (20 yo male)
- The desire to be normal – big issue, esp. for the younger ones
 - *"...sacrificing your perfect A1c to like, have a good time with your friends because like, at the end of the day you want to be like a normal college student too."* (20 yo F)
- Finding a balance between diabetes and life was challenging for all



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Finding a Balance (contd.)

- Diabetes as a secondary concern when confronted with a new situation such as college or work:
 - *"Last year, when I was starting to figure everything out, it was lots of peaks and valleys, since I was on such an intensive course list. So I wouldn't really think too much about diabetes. It would be more of 'I need to study, I need to get ready for this exam, I need to get all my homework done. I don't wanna be that guy to not do anything in college.'" (20 yo M)*
 - Some intentionally ran BG's higher temporarily
 - Everyone acknowledged they were doing this when they did this and strove to get their BG's back in target range again soon



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Finding a Balance (contd.): Living Situation's Effect on DSM

Living at home better	Living away from home better
<ul style="list-style-type: none"> • In a familiar place • Has a better schedule at home • Easier having parents around • Central location for BG meter at home – makes it easier to check • More snacking at college • College food made it difficult to keep BG's in range • College life made BG control difficult • Stressed out by college • Diabetes as a secondary concern during the first years of college (for some) – school took priority 	<ul style="list-style-type: none"> • More comfortable/relaxed at home – let BG's go/less concerned about staying in range when at home, because around people who understand diabetes • Better schedule at college than at home • "Forced me to pay attention" • "Allowed me to be in control of the situation" • More snacking at home/more snacks available at home • Goes out more with friends at home

"At the beginning of college it [my BG] was all up and down." (23 year-old female).

"It's when you're alone, whether it's in college or the first time you're being away from your parents, and you realize that you know, you're kind of all you have to take care of yourself. That's the first time when you're like, 'My parents aren't around, I can't do these things I used to do when I was younger'." (25 year-old male).

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Finding a Balance - Work

- Did not want to seem less capable at work because they had diabetes (females)
- Those who worked in the service industry (teaching, health care, nanny, coffee barista) found it difficult to take care of themselves when they were supposed to be taking care of someone else
- Males – did not find this to be as big of an issue as the females



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Finding a Balance - Identity

- *"It's a huge part of my life, and I'm not denying that, but it's very much not who I am. I'm not like C the diabetic, I'm like C, I happen to have diabetes, it's something I've dealt with just about my whole life. But that doesn't have to be who I am."* (22 yo F)



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2. The Desire to be "In Control" of Their Diabetes

- Self-reported HbA1c: 
 - <8%: 71% of participants
 - ≤7%: 43% of participants
- All strove to achieve optimal glycemic "control" but this was accompanied by much frustration, esp for the males and younger females
 - *"You can't even, like, I can't just run out to the grocery store, I have to bring all my shit with me. Like, everything you do, like, when I go to work, I'm like, all right, I'm going to be gone for 14 hours, do I have enough insulin, do I have extra, what if this fails, what if that..."* (20 yo F)

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**Desire to be "In Control" (contd.):
Reasons for Diabetes Mismangement**

- The desire to be normal or fit in
 - More of an issue for the younger subset (both M & F)
- Privacy/secretcy about their diabetes
- Fear of hypoglycemia
- Just giving up for a moment



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Desire to be "In Control" (contd.)

- Privacy/secretcy
 - Did not want those around them to know about their diabetes
 - Did not want the extra burden of explaining about diabetes at that time
 - Occ. fear of how those around them might react to DSM tasks:
 - *"It's so much as having social anxiety to jus take it out and measure in like a college classroom. I know nobody cares, I know nobody's looking, but, it's just that little beep from the monitor, and like I'm obviously, I'm drawing blood from my finger, so someone would be like, 'What's that guy doing?' So....it's just that little aspect of social anxiety, that sometimes keeps me from measuring it in class."* (21 yo M)
 - Benefits of diabetes camp



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Desire to be "In Control" (contd.)

- Fear of Hypoglycemia (FOH)
 - Pervasive throughout every situation for all females
 - Biggest fear for many females regardless of their HbA1c
 - Hypoglycemia described as scary, problematic, annoying, frustrating, and interfering with normal functioning: *"Going low is so inconvenient....When I'm low I literally have to stop what I'm doing because my vision gets really blurry, I shake, like, all those symptoms you have...so that's why for a while I was scared of going low."* (20 yo F)
 - Some ran BG's higher to avoid hypoglycemia
 - FOH caused anxiety
 - Those with actual FOH had 1) hx of severe hypo or 2) new someone who had a bad outcome from hypoglycemia
 - Females reached out to others for help with low BG; all 6 males and 2/3 Black females generally did not seek assistance from others
 - Males not as bothered by hypoglycemia as females unless they had history of severe hypo or were in a situation without available treatment



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Desire to be "In Control" (contd.)

- Use of diabetes technology (pumps, sensors, DIYP) 
 - Helped greatly, but not without its own frustrations
 - CGM seen as *"a safety thing, a sort of insurance that someone knows you're alive, they can watch you and see/intervene if there is a problem."* (26 year-old F)
 - Constant reminder they had diabetes (younger females, no camp)
 - Males: bothered by having bulging pockets from all of the devices they needed to carry
 - Technical issues:
 - Having phones/beeping in class

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3. The Hidden Burden of Diabetes 

- Need for constant attention to their diabetes – issue for all females (n=15)
 - *"It's like you're not dying, and you're fine, but like also, like, there are times when you're really low and you're like 'oh! Am I ok?'"* So it's kind of hard to...for people to actually like under stand and grasp like how serious it can be. Because like, people always see me like 'oh, I forget you have diabetes' and I'm like 'I don't because its on my mind 24/7' so that can be challenging too." (20 yo F)
- Drinking alcohol:
 - Difficulties with BG management: *"I have to make sure I wake up in the morning"* (23 yo F)
 - Did not want to be a burden on their friends: *"If they [my friends] are drinking too I can't be their responsibility"* (20 yo F)
 - Females did not like feelings of loss of control with hypoglycemia or with drinking
 - Males reported they were in control of the situation most of the time

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The Hidden Burden of Diabetes (contd.)

- Not wanting any special attention because they had diabetes:
 - 6 males all felt this way – more emphatic about their independence and the ability/desire to take care of everything on their own
 - Male outlook on independence with DSM and not involving or engaging others in their care shared by 2/3 Black women and the transgender female as well
- White & Hispanic women and 1 Black woman more likely to involve others in their care 

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4. The Desire to Have a Connection With Their Diabetes Provider

- Approx ½ of the study participants were still seeing their Peds Endos
 - Not yet aged out of pediatric services
 - Provider saw adults as well
 - One individual said she had "yet to hear a great transition story"
- Peds Endos = family members
- Liked diabetes providers who engage them in conversation instead of talking down to them



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The Desire to Have a Connection With Their Diabetes Provider (contd.)

- Ideal diabetes F/U program
 - Connection with their diabetes provider desired by ALL
 - Providers as partners in care
 - Trust
 - Comfortability
 - Effective 2-way communication
 - See the whole person: *"Having someone that would understand all the different components of like your body, and your life, and like, ok, you're going to school, or you're changing jobs, or whatever you're doing, and be able to incorporate all parts of you into your care. That would be like, ideal."* (22 yo F)



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The Desire to Have a Connection With Their Diabetes Provider (contd.)

- Ideal diabetes F/U program (contd.)
 - Increased availability and accessibility of diabetes providers
 - Evening visits
 - Weekend visits
 - Longer appointments
 - Easily accessible by phone and e-mail
 - Interdisciplinary visits, incl. more mental health assessment
 - Provider knowledge about the latest in diabetes technology treatments



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The Desire to Have a Connection With Their Diabetes Provider (contd.)

- In-person F/U visits unanimously preferred over virtual visits
- Virtual visits useful in certain situations:
 - Far from clinic (away at school, traveling)
 - Busy with work or school and cannot get away to come in
 - A quick question that needs a visual
 - Emergencies
 - A quick introduction to a new provider
 - Pump upgrade trainings for experienced pumpers
 - Regular F/U visit once in a while if there were no new issues to discuss



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Male/Female Differences

	Males	Females
Attention	Did not want any special attention because they had diabetes	Ok to get special attention because they had diabetes
Hypoglycemia	Felt in control of the situation most of the time	Did not like feelings of loss of control with hypoglycemia or with drinking
Fear of Hypoglycemia	Only an issue of h/o severe hypo themselves or not able to treat a low BG	Pervasive throughout every situation
Engaging others	Did not involve or engage others in their care (also true for 2/3 Black women and the transgender female)	Likely to involve others in their care (except for 2/3 Black women and the transgender female)

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Discussion



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Study Strengths

- Desire to have a connection with their diabetes provider has not previously been described in the literature
- Diversity of study participants
 - 33% ethnic minorities
 - Non-Hispanic White included one transgender female, one Orthodox Jewish woman, and one young man born of immigrant parents



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Helpers

- Diabetes Technology
 - Insulin pumps
 - CGM
 - Apps (+/-)
- Diabetes Camp
 - Helped to integrate diabetes into their identity
 - Helped to decreased the developmental challenges they faced



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Limitations

- Difficulties with recruitment
 - Males
 - Data redundancy not reached with males
- Communication
 - E-mail
 - Text messaging and Facebook messenger
- Study participants may be a self-selected group of motivated volunteers
 - Findings consistent with what is in the literature
 - Findings add the perspective of ethnic minorities



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Conclusions



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Conclusions



- Despite the challenges they faced, the emerging adults in this study had a strong desire to have optimal diabetes management
- Everyone had a hard time balancing DSM with all of the other competing priorities in their lives
- Most desired features for clinical follow-up services:
 - Connection with their diabetes provider
 - In-person visits
 - Be treated as a partner in care
- Different groups of individuals had different perspectives on living with diabetes and different approaches to DSM

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Future Research

- Exploration of the variation in perspectives from emerging adults with T1DM who are:
 - ethnically/culturally diverse
 - Males
- Persistence of male/female differences in larger samples
- Strategies to recruit young adult males into research studies
- Determination of what sorts of tailored interventions can help this vulnerable group do better with their DSM during this challenging time

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Implications for Diabetes Educators



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Implications for Diabetes Educators

- Understand the challenges that emerging adults face so clinicians can offer appropriate anticipatory guidance
- Take differing perspectives based on gender, race/ethnicity, and culture into account
- Easier to recommend different tools and/or strategies for the emerging adult with T1DM to use if the issues they face are understood
- Understand that a seeming lack of sufficient attention to DSM behaviors is not necessarily due to negligence
- Transition services: building a good relationship between provider and client is key for success



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Questions?

E-mail: news@rorymeiers.com

When you first get diagnosed with Type 1 Diabetes..

Many years later..

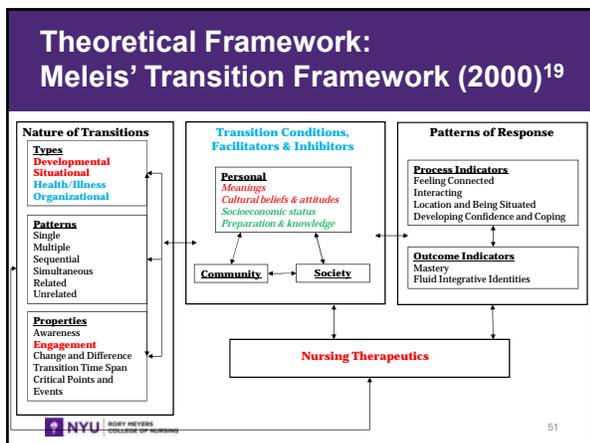
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Thank you!

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