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Diabetes Management and Self-Care among Emerging Adults: Emerging Adult and Diabetes Care Provider Perceptions of Self-Management Influences, Visit Interaction, and a Tool to Enhance Diabetes Care at Visits

By

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Doctor of Philosophy

Nursing

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B.S., Davidson College, 2000
M.P.H., Emory University, 2007
B.S.N., Kennesaw State University, 2013

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An abstract of
A dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy
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Abstract

Diabetes Management and Self-Care among Emerging Adults: Emerging Adult and Diabetes Care Provider Perceptions of Self-Management Influences, Visit Interaction, and a Tool to Enhance Diabetes Care at Visits

By Rachel A. Wolf

Background: While the number of emerging adults with diabetes (EAWD) increases, health outcomes among EAWD remain suboptimal with frequent rates of poor glycemic control. Interventions are needed to facilitate age-appropriate care for EAWD. Event history calendars (EHC) have been used to facilitate patient provider communication and contextualized care. The purpose of this study was to investigate perspectives of EAWD and healthcare providers regarding diabetes self-management influences and EAWD-provider diabetes visit interactions and to develop an EHC tailored for EAWD diabetes care visits.

Methods: The study used a mixed method exploratory sequential design. Focus groups and interviews with EAWD and interviews with healthcare providers from a public healthcare system were conducted to identify influences on self-management as well as perspectives on current and desired interactions with diabetes providers. Qualitative findings were used to inform EHC development. In quantitative follow up, EAWD and providers reviewed the EHC for content validity, feasibility, and utility for clinical use, including cognitive benefits for EAWD and communication benefits for EAWD and providers.

Results: EAWD and providers both identified intrapersonal, interpersonal, and structural influences on diabetes self-management. Both EAWD and providers described psychological burden complicated by life stage tasks and responsibilities associated with emerging adulthood as well as resource barriers to optimal management. Providers perceived lack of EAWD engagement as a challenge to EAWD care. Both EAWD and providers perceived that additional value could be gained from EAWD-provider interactions and valued the importance of the EAWD-provider relationship in care. The EHC was well received by EAWD and providers in regard to feasibility and utility. EHC topics rated as highly relevant by both EAWD and providers included diabetes supplies, medications, physical activity, stress, and diet. Several other EHC topics may require additional review, and feasibility could be improved with revision.

Conclusions: EAWD and providers value tailored, contextualized information for diabetes care. With additional assessment and development, an EAWD specific EHC may provide a feasible tool to improve diabetes care and communication for EAWD at diabetes visits.

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Acknowledgements

Successful presentation and defense of a dissertation is intended to signify the achievements of a PhD candidate, but it very much reflects upon a large number of individuals both past and present who have supported and nurtured that candidate throughout his, her, or their lifetime and allowed him, her or them to achieve this milestone.

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Introduction

Specific Aims

Diabetes impacts over 22.3 million people in the United States at a cost of $245 billion per year in direct and indirect costs, 24-45% of which result from complications of the disease.[1] At least 1 million youth and young adults in the United States have diabetes. The incidence of both Type 1 and Type 2 diabetes in youth and young adults is expected to continue to rise in the next few decades.[1,2] Early adulthood is an important time to establish lifelong healthy self-management behaviors in order to delay or prevent acute and long-term complications resulting from poor glycemic control.[3,4] However, few emerging adults with diabetes (EAWD) achieve recommended glycemic control. Although the American Diabetes Association has recognized a need to establish recommendations for diabetes management strategies among EAWD, there is a lack of research among EAWD to guide the development of such recommendations, including management strategies among minority and socioeconomically diverse EAWD.[5]

The goal of this research study was to improve the health of minority and socioeconomically diverse EAWD by developing a tool based on qualitative and quantitative data that supported EAWD care at diabetes visits. The tool was designed to facilitate EAWD and diabetes health care provider (provider) cognition, or awareness, of the unique context surrounding a patient's diabetes self-management and enhance the quality of EAWD-provider communication. To this end, the study explored perspectives of EAWD and providers regarding specific life topics that should be addressed during routine EAWD healthcare visits for diabetes management (contextualization of care). Topics identified as relevant to contextualization of diabetes management and clinical care conversations were incorporated into an event history calendar (EHC), an innovative tool designed to present details of EAWD life circumstances in a format that facilitates cognition and communication regarding determinants of diabetes management.

EAWD continue to mature socially and psychologically while assuming greater independence and responsibility in balancing various competing demands that include navigating multiple life transitions.[6] Therefore, interventions designed to address the unique circumstances of EAWD may be especially important in overcoming diabetes management challenges among EAWD. The majority of interventions to date target the transition from pediatric to adult care rather than the needs of EAWD after transition to adult care.[7] There is a dearth of empirically based approaches that enhance management among EAWD within adult care. However, exploratory research suggests that approaches focusing on patient-provider communication that enhances patient-provider partnership and life stage appropriate interaction may facilitate better EAWD self-care and overall management by promoting disclosure of risk-taking behaviors while increasing problem-solving and tailoring of care to a patient's broader life context. [8–12]

Use of EHC is an approach well-suited to facilitate patient-provider communication. EHC aid both patient and provider in care contextualization by presenting past experiences, behaviors, and life events in a calendar-like format.[13] Patients provide details about different topics of inquiry (such as work, family, social activities) in a manner that enhances autobiographical recall. Because of their ability to enhance recall and provide context for behavior, EHC have been developed for emerging adults in other healthcare settings. Visualization of life context appears to benefit patients directly in identifying self-management challenges as well as indirectly through quality of patient-provider interaction; data from these studies demonstrate that EHC improve patient-provider communication, risk factor disclosure, problem-solving, and patient and provider satisfaction with care.[14–16]

However, no EHC reflective of life context specific to needs of EAWD and their providers has been developed. Findings from prior studies among EAWD provide some guidance regarding aspects of patient-provider communication and concerns relevant to EAWD, but this research is not specific to either the perspectives of minority and socioeconomically diverse youth and their providers nor the goal of EHC development. Therefore, obtaining data from EAWD and providers regarding topics pertinent to communication and contextualization of diabetes management through EHC was needed to maximize EHC utility among this population. Therefore, this research project included three specific aims:

Aim 1: To explore the perspectives of EAWD and providers regarding EAWD diabetes self-management and patient-provider communication about diabetes management during diabetes care visits among minority and socioeconomically diverse EAWD

Aim 2: To develop an EAWD specific EHC based on topics identified by EAWD and providers as relevant to addressing EAWD diabetes care and management at diabetes care visits

Aim 3: To assess content validity of the EHC, feasibility, and clinical utility of using an EHC approach to improve EAWD-provider communication and cognition of patient life context during diabetes care visits

In broader context, this research supports the mission of the National Institute of Nursing Research (NINIR) to provide personalized self-management interventions for individuals with chronic conditions and to reduce health disparities.[17] The outcome of this study was an EHC tailored to the unique needs of disadvantaged EAWD and their providers that can be further refined to maximize the use of an EHC approach to improving clinic visit outcomes for diabetes management, and ultimately, facilitating quality of life and optimal diabetes health outcomes among minority and socioeconomically diverse EAWD.

Background and Significance

Diabetes among young adults- A growing problem: Diabetes is a leading cause of morbidity and mortality in the United States and contributes to the rising burden of healthcare expenditures at an estimated cost of one of every ten healthcare dollars.[1] Approximately 25 out of every 10,000 U.S. youth had received a diagnosis of type 1 or type 2 diabetes in 2018.[18] The incidence of type 2 diabetes continues to rise in the United States at an estimated rate of 5,000 new diagnoses in youth per year.[19] Therefore, a growing number young adults age 18-30 will be living with diabetes. These trends reflect an increasingly important healthcare concern, especially among minority and socioeconomically diverse populations.[18,19] Yet findings from studies of glycemic control and self-management among EAWD suggest that diabetes among this group is associated with risk factors for short and long-term complications.[4,5,20–22] Health outcomes among disadvantaged EAWD tend to be worse than other EAWD, including poorer psychosocial outcomes and glycemic control.[23,24] Minority emerging adults are at greater risk for emergency hospitalization.[25] Yet little research on minority and socioeconomically diverse EAWD is available to guide effective intervention.[7,11]

Emerging adulthood- A time of transition: Individuals between the ages of 18 to 30 are not just "young adults." Because of social changes in the last few decades, this age has been identified as a distinct life stage known as emerging adulthood. Criteria identified by emerging adults as indicators of adult status include accepting responsibility for self and making independent decisions, yet not until their late twenties or early thirties do most individuals identify entirely as adults.[6] Emerging adulthood is characterized as a transitional stage which represents the age of greatest demographic heterogeneity and fluidity within domains such as work, education, and relationships. In emerging adulthood life patterns are established that impact diabetes-related quality of life, morbidity, and mortality, especially given the importance of early and ongoing optimal glycemic control in preventing later complications.[26] Findings from studies suggest that understanding the importance of this key period and the ways in which domains such as family, peers, and identity development intersect have implications for health outcomes during and after emerging adulthood.[27]

EAWD- Unique challenges to diabetes management: While much diabetes research focuses upon youth with Type 1 diabetes or older adults with Type 2 diabetes, research is beginning to elucidate challenges for EAWD in managing diabetes. For instance, cognitive development continues well into the second decade, so EAWD are continuing to develop cognitive capacities such as problem-solving skills and executive processing skills that allow them to better manage diabetes. In adolescence, parents continue to facilitate care, and among EAWD parental guidance may still be protective, even as EAWD gain greater independence.[28] Problem solving in adults and children with diabetes is associated with better psychosocial and health outcomes. Collaborative problem solving with providers has been proposed to improve EAWD outcomes.[23,29] Problem solving skills among EAWD also appear protective against decreasing glycemic control.[30] Data indicate that executive function tasks such as impulse control are associated with better outcomes among EAWD.[31] Yet, risk taking behaviors such as drinking, illicit drug use, and risky driving are highest among emerging adults.[6] For EAWD, risk taking may pose additional threats. Correlates of hospitalization for diabetic complications include risk behaviors such as alcohol abuse as well as mental health issues.[31,32] In an investigation of eating behaviors among EAWD, 20% of participants were found to have disordered eating behaviors.[33] However, EAWD report lack of disclosure of risk behaviors to providers, suggesting a need for improved communication during clinic visits.[8] EAWD also experience higher levels of diabetes-related distress, and higher distress has been correlated with socioeconomic disadvantage among this population.[21,34] EAWD report unpredictable schedules and competing priorities which require renegotiation of self-management.[9,35] Diabetes care is often reprioritized to balance work, family, school, and peer relationships; learning to self-manage in the context of these life changes includes recognizing patterns and learning from experience.[35] Among minority and socioeconomically diverse EAWD these challenges are compounded by socioeconomic barriers to managing diabetes as an adult.[11] Peer influence, sense of invincibility, and financial barriers also affect EAWD decision making.[9,36,37] Thus a combination of interrelated factors including cognitive development, risk taking, navigation of adult responsibilities, and understanding behavior in context influence diabetes management among EAWD. Tailoring care to the specific context of these life circumstances appears to be a salient target for intervention to enhance management and glycemic control among this cohort.

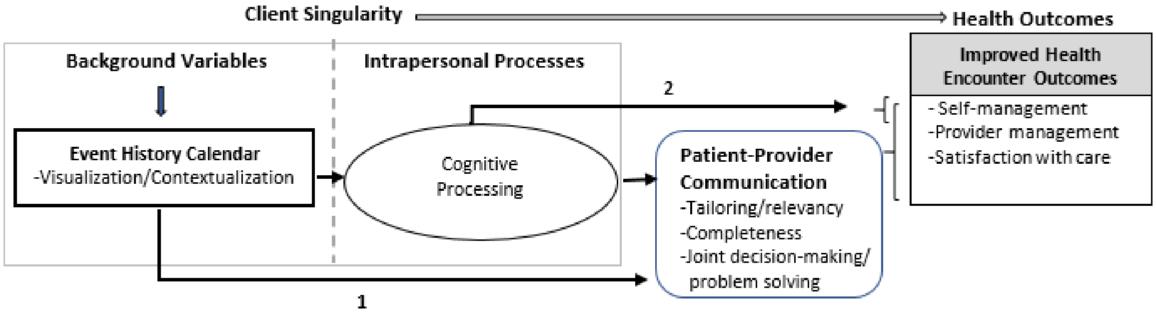
Healthcare for EAWD- A need to adapt: Because EAWD transitioning from pediatric to adult care must adjust to a new model of care, interventions focused on improving quality of patient care for EAWD often target the transition from pediatric to adult care.[7]. Pediatric care tends to be parent-centered and team based with a family approach, whereas adult care is patient-centered in that the patient is expected to take full responsibility during healthcare visits and for self-management outside the healthcare setting.[20,38] Adult diabetes care focuses less on psychosocial concerns and more on glycemic control and risk for long term complications.[5,23] This transition is often abrupt and is itself a risk factor for poor glycemic control.[20,39] Structured transition programs that facilitate care coordination and developmentally appropriate care within young adult specialty clinics to assist EAWD in their diabetes care improve clinical outcomes such as increased follow up care, lower HbA1c, and reduced hospitalization rates for hyperglycemia.[40–43] However, not all EAWD (especially Type 2) transition from pediatric to adult care, and clinics serving primarily minority and socioeconomically diverse EAWD may not be able to implement these more resource intensive programs. Moreover, the adult care patient provider visit is often not a target of intervention. Providers do have access to some screening tools to identify psychosocial concerns such as disordered eating behaviors among patients with Type 1 diabetes.[33,44] Other provider tools include the Diabetes Quality of Life Questionnaire, designed to identify quality of life issues, enhance communication, and provide actionable measures for providers during routine visits.[45] Such screening tools begin to enable providers to identify EAWD needs and offer guidance in tailoring care but are not designed specifically for EAWD, nor do they obviate the need for greater understanding of patient concerns and issues.[45,46] Even when these tools are used for problem identification, further conversation and contextualization are often warranted to facilitate meaningful intervention.

Patient-Provider Communication- Opportunity to improve outcomes: Given the dynamic context of EAWD life challenges and the current deficit of resources in adult care to provide age appropriate care, additional intervention is needed within adult care environments and particularly through facilitation of communication between EAWD and their adult providers. Communication between healthcare providers and patients in general has been shown to impact many facets of patient care, including patient satisfaction, medication adherence, self-management, and health outcomes.[47–53] Yet minority and socioeconomically diverse populations are at greater risk for poor patient-provider communication[54–57] Among EAWD, loss to follow up has been associated with perceived lack of support from providers and perceived lack of value of routine clinical visits.[5,58,59] Providers themselves express concern about their lack of knowledge regarding how to care for the needs of younger adults.[58,59] Provision of anticipatory guidance is an important function of providers; higher levels of anticipatory guidance are associated with higher quality of life and satisfaction with healthcare among EAWD.[60] Yet low levels of guidance have been reported for topics such as pregnancy.[60] Contextualization of a patient's broader psychosocial and built environment through communication may be helpful in facilitating needed guidance and more appropriate diabetes management. While self-management may be less than optimal, EAWD often report a desire to engage in better self-care but needing open, honest communication with providers in order to develop workable solutions through shared decision making.[8,21,35] Therefore, optimal EAWD provider communication must be viewed as essential for provision of tailored developmentally appropriate diabetes care.

<u>EHC- An approach to enhance care during the clinical visit:</u> EHC are brief documents (paper/pencil or web-based) completed by the individual and then reviewed with the provider to facilitate discussion of specific life context (e.g. relationships between events and behaviors). EHC have traditionally been used in sociological and survey research to facilitate accuracy and completeness of life event research. EHC collect information regarding life topics of interest (i.e. work history, stressors, social activities) bounded within discrete units of time (i.e. weeks, months, years). The nature of the topics and timeframe differ by setting and population. Use of EHC enhances autobiographical memory through sequential recall of temporally-related events and parallel recall of related events within different life topics.[13] In research and education, EHC have been used not just as a recall tool, but as a tool for reflection and discussion.[61,62] Limited research has been conducted on use of EHC in clinical settings but suggests a role for EHC in improving patient-provider communication and quality of care. Compared to a standard adolescent health screening questionnaire, EHC lead to better patient-provider communication in terms of viewing the patient in context, developing shared understanding of patient preferences and needs, and enabling patients to assume a greater role in the interaction.[63] In prenatal care settings with young adults, EHC have been well received by patients as a means of addressing patient concerns and goals.[16] Moreover, the visual contextualization and linking of behaviors to context and time within EHC is perceived by both patients and providers as an especially helpful mechanism to promote awareness, problem-solving, and tailored care.[14,15,63] Particularly relevant to EAWD, EHC use enhances disclosure of sensitive topics such as smoking and sexual risk behaviors among adolescents and drug use patterns among opioid users.[15,64,65] Evidence also supports the feasibility of utilizing EHC during routine outpatient visits. EHC have been successfully self-administered to participants of varying ages and literacy. Patients report average completion times of 5-15 minutes and perceive EHC as easy, and even enjoyable, to complete.[13–15,54] Initial reports related to clinician burden are promising; in one study, clinician review of EHC and identification of risk behaviors took two minutes on average.[15] In another study, clinicians perceived EHC as not only conducive to clinic flow but a more feasible strategy to serve the needs of their low-income clients.[64] While no EHC has been designed for EAWD, EHC potential to contextualize and link events, improve disclosure and problem-solving, and promote tailored communication merits further investigation.

Theoretical Framework

Figure 1. Theoretical Framework



The Interaction Model of Client Health Behavior (IMCHB) was adapted for use as a theoretical framework in this study as it acknowledges the roles of a) the uniqueness of the patient and b) patient-provider communication in health outcomes (Figure 1). IMCHB incorporates three major constructs: client singularity (the uniqueness of the individual), client-professional interaction, and health outcomes. Client singularity comprises both background variables and variables related to unique individual intrapersonal processes. Background variables include such factors as demographic characteristics, social influences, and personal resources that may affect intrapersonal processes, communication, and health outcomes. Likewise individual intrapersonal processes such as cognitive appraisal and affective responses influence communication and health outcomes.[66] This study focused on one intrapersonal process, cognitive processing. Additionally, client-professional interaction was redefined as patient-provider communication to represent interaction within the clinical setting.

The goal of the study was to develop an EHC inclusive of EAWD life context that delineates pertinent background variables of client singularity. As illustrated in Figure 1, EHC may provide a medium for contextualization and visualization of information and events (background variables) relevant to EAWD diabetes management that improves aspects of patient-provider communication and, ultimately, healthcare visit outcomes. A second mechanism by which EHC were posited to impact healthcare visit outcomes is via cognitive processing. Facilitation of cognitive processing by EAWD through EHC should increase awareness of the relationship between life events and diabetes management. This learning experience was posited to directly improve self-management and to indirectly improve self-management and other health outcomes through improved patient-provider communication. Study Aim I was to elucidate background variables for inclusion in an EHC, leading to EHC development (Aim II), while Aim III addressed initial assessment of the relevance of topics presented in the EHC and of ways EHC may improve outcomes through enhanced cognitive awareness and communication.

Summary and Scientific Premise

Diabetes management and health outcomes among EAWD are suboptimal. Interventions are needed to address the specific needs of this population. Patient provider visits provide opportunity to improve care through improved communication and care contextualization. EHC have been shown to enhance care via these mechanisms. While well received by patients and providers in several other settings, no EHC has been developed for diabetes. An EAWD-specific EHC is a potentially pragmatic, effective tool with limited cost and burden to patient and provider that can be integrated effectively within routine outpatient visits. This study incorporated the perspectives of both the patient and the provider in developing a novel tool for EAWD to illuminate richer psychosocial and ecological context for tailored care within the limited timeframe of outpatient visits. The study aligns with the mission of NINR in that it targets the needs of a primarily minority and socioeconomically diverse population within an urban public healthcare setting to guide development of meaningful chronic disease intervention for underserved, understudied patient populations.

Approach

Research Design: The study used a two-phase exploratory sequential mixed method design to develop and pilot an EHC for EAWD.[67] The initial phase consisted of data collection through focus groups and interviews with EAWD and interviews with providers using a qualitative descriptive design to address Aim 1.[68] An EHC was then developed (Aim II) based on qualitative data analysis. Aim III was addressed in the second phase of the study, during which the EHC were completed by EAWD and reviewed by providers, and quantitative EHC questionnaires were administered to EAWD and providers to assess the EHC in regard to content validity, feasibility for clinical use, and utility for diabetes management (Table 1).

Table 1. Study Activities and Sample Size Goals

Study Phase	Activities	Emerging Adult Target #	Provider Target #
Phase I (Emerging Adults)	a. Demographic questionnaire b. Focus groups/interviews (as needed)	20-30 (4-6 focus groups)	n/a
Phase I (Providers)	a. Demographic questionnaire b. Interviews	n/a	10-12
EHC Development			
Phase II (Emerging Adults)	a. EHC completion b. EHC assessment questionnaire	10 from Phase I	n/a
Phase II (Providers)	a. EHC review b. EHC assessment questionnaire	n/a	6-9 from Phase I

Sample Recruitment:

Target Samples/Sample Size- The target samples were EAWD (18-30yrs) with a Type 1 or Type 2 diabetes diagnosis receiving medical care at public healthcare systems and endocrinologists and diabetes nurses providing outpatient care for EAWD at public healthcare systems. Estimated sample sizes for EAWD and providers qualitative recruitment (Table 1) were based upon prior research regarding EHC development and minimum sample sizes required to identify the majority of themes in focus groups and interviews.[69,70] Sample sizes for quantitative phase data collection were based upon recommended number of experts required for content validity assessment.[71]

Inclusion/Exclusion criteria- EAWD had to be between 18-30 years, have had a diagnosis of Type 1 or 2 diabetes for at least one year, speak English, and have received adult outpatient diabetes care at the Grady Diabetes Center in Atlanta, Georgia. EAWD could not have cognitive or developmental disabilities precluding focus group participation, as determined by ICD codes from chart review. Providers had to be currently caring for Type 1 and 2 diabetes at the Grady Diabetes Center. Provider exclusions included not treating EAWD within the past six months, as assessed by provider self-report.

Sampling/Recruitment Method- *EAWD:* EAWD were recruited through convenience sampling using multiple strategies based on researcher access to a large sampling frame within Grady Healthcare System, a public urban healthcare system serving a predominately lower-income Black population. EAWD recruitment occurred primarily via letters mailed to eligible EAWD. Letters were mailed in waves at intervals to all EAWD who meet eligibility criteria as identified by electronic medical records (EMR) from November 2018-November 2019. Patients were invited to call or return a card indicating interest/disinterest in the study using a prepaid envelope. Follow-up calls were made to non-responders. The principal investigator also attended a Grady Diabetes Center nurses’ meeting to inform diabetes clinic nurses of the study and invite them to refer EAWD to the study. Study informational flyers were distributed to Grady Diabetes Center nurses and front desk staff for distribution to EAWD patients. Flyers were also posted in the Grady Diabetes Center waiting room. As EAWD recruitment is challenging, this multi-arm recruitment strategy was used to maximize sample size within the study timeframe and budget. All EAWD were asked at the end of focus groups or interviews to indicate interest/disinterest in participating in phase two of the study (EHC assessment). At the initiation of phase two activities, attempts were made to contact all interested EAWD participants by phone to confirm interest in EHC assessment and proceed with phase two EHC assessment activities. EAWD received $25 cash compensation for focus groups and interviews and $25 gift certificates for EHC assessment. *Providers:* Providers were recruited via convenience sampling. An e-mail was sent to Grady endocrinologists and diabetes nurses providing outpatient diabetes care at Grady Diabetes Center. Follow up e-mails were sent to non-responders. Providers were provided with a token of appreciation ($5 gift card) for their participation.

Alternative Plans/Attrition: It was expected that about 20% of EAWD and 70% of providers would agree to participate. EAWD recruitment cards included questions regarding reason for not participating so that participation barriers could be addressed. The principal investigator attempted to schedule seven to nine participants per focus group, in estimation that 50% of EAWD would attend. For those EAWD not available to attend a focus group or uninterested in attending a group discussion, individual interviews were offered. Confirmation letters were sent to EAWD scheduled for a focus group or interview, and reminder calls were made the day prior to all EAWD focus groups and interviews. Those not attending their scheduled focus group or interview were contacted to reschedule their visit, if desired. Additional efforts to recruit providers included one on one contacts with Dr. Haw, a member of the principal investigator's dissertation committee and a Grady Diabetes Center endocrinologist. Retention Plans- Preferred method of contact and contact information for EAWD were collected at recruitment and reconfirmed during focus groups/interviews. The research team attempted to build rapport and recognize participants as partners in EHC development. Healthy snacks and monetary incentives were provided to EAWD participants. Participant burden was reduced through flexible scheduling to complete or review EHC and complete EHC assessment questionnaires.

Study Procedures: Phase I (EAWD Focus Groups & Interviews/Provider Interviews)- EAWD focus groups were held in the evening or weekend in a classroom at Grady main campus over a two-month period. For those EAWD scheduled for individual interviews, interviews were held in a main campus classroom or private room at the Diabetes Center at a time chosen by the participant. EAWD were consented individually by the principal investigator or a research assistant upon arrival at Grady for their focus group or interview. EAWD were provided with paper consent documents to review, but oral summaries of the consent were also provided to account for potential literacy challenges. Brief paper and pencil demographic questionnaires were administered at the beginning of focus groups and interviews. The focus group moderator and a research assistant were present to assist with focus groups. Questionnaires were checked for completion at the time of the focus group/interview to reduce the potential for missing data. A total of five focus groups were scheduled, with show rates ranging from one to five participants. The principal investigator conducted all focus groups and interviews. A research assistant with demographic characteristics similar to the patient population was trained by the principal investigator to assist with focus groups, monitor time, and take notes during focus group discussions. Focus group ground rules were presented as suggested by Krueger and Casey.[72] Provider interviews were conducted by the principal investigator at Emory or Grady main campus at a time convenient for providers. Interviews and focus groups were audiotaped and transcribed verbatim, with the exception of one focus group that was not recorded due to principal investigator error.

<u>EHC Development</u>- After conclusion of qualitative data collection and analysis, an EHC was developed by the study team, including an expert in EHC design (Dr. Martyn) and an expert in mixed methods measurement (Dr. Kimble), based, in part, on themes identified from the qualitative data analysis as described by Yi, Lori, and Martyn.[70] Themes were presented as topics within the EHC and prompts within each topic of inquiry were developed to solicit contextual information identified as relevant to enhancing quality of EAWD-provider communication for diabetes management, guided by qualitative data content analysis. It was expected that discrepancies could emerge from EAWD and provider data analysis and that the number of topics identified might exceed the number that could reasonably be presented within an EHC. Preference for EHC inclusion was given to themes common to both EAWD and providers. Other criteria for EHC inclusion included topics felt to be most pertinent by participants and those most amendable to intervention during EAWD-provider interaction. Time intervals of inquiry (e.g. weekly, monthly) regarding each topic was determined based upon topics to be included and participant

preferences identified during qualitative data collection. A draft EHC underwent study team review (Dr. Kimble, Dr. Martyn) and was revised by the principal investigator prior to preceding to EHC assessment.

Phase II (EHC Assessment)- The second phase of data collection commenced approximately six months after qualitative data collection ended. EAWD*:* This phase began with EAWD EHC completion and questionnaire administration (Table 1). Attempts were made to contact each EAWD interested in EHC assessment via phone to arrange a phone visit at a time convenient for the participant. EAWD interested in this phase of the study were mailed a packet with the draft EHC, an EHC assessment questionnaire, and instructions for EHC completion. During the phone visit, EAWD were consented for EHC assessment prior to study activities. EAWD were then asked to read EHC completion instructions and complete the EHC. The principal investigator recorded the time it took participants to complete the EHC and then verbally administered the EHC assessment questionnaire and recorded participant answers. EAWD were asked to return the completed questionnaire via mail. Data collection for EAWD occurred over two months, after which provider EHC assessment commenced. Providers: After confirming interest in EHC assessment via e-mail correspondence, the principal investigator mailed an EHC assessment packet to interested providers. Three representative de-identified EAWD completed EHC were selected for review by all providers. Along with the completed EHC, providers received written instructions for EHC review. Providers were invited to make notes or comments on the EHC regarding their observations or thought processes as they review the EHC. Immediately following EHC review, providers completed an EHC assessment questionnaire parallel to that given to EAWD and returned the EHC and questionnaire to the study team via mail.

Instrumentation/Techniques: Semi-structured focus group guides and interview guides were used to collect data addressing Aim I in the qualitative phase of the study (Table 2). This allowed for exploration of perspectives in a manner that was flexible yet directed towards developing understanding of the most relevant topics and timeframes for inclusion in an EHC. EAWD Focus group and interview discussion topics were adapted from a prior study using focus groups to develop an EHC for prenatal care.[70] The moderator and research assistant debriefed after focus groups to review findings and discuss any needs for revision of the focus group guide. Provider interview guide topics were written to parallel the content of EAWD focus group/interview topics but were modified to explore the perspective of providers. Providers were also specifically asked to provide feedback regarding topics that should be included in an EHC designed for EAWD. In order to facilitate provider conceptualization of EHC and address this question, a mock EHC was presented to providers during interviews along with a brief explanation of how EHC may be used to aid in communication and cognitive processing. Provider interview topics were piloted and revised during a mock interview with a Grady Diabetes Center Endocrinologist (Dr. Haw). Following the first few interviews with providers, the principal investigator and Dr. Kimble meet to discuss any need for revision of the focus group/interview guides and address challenges or inconsistencies in data collection to enhance dependability/credibility. Questionnaires were used to collect demographic data from EAWD and to collect EHC assessment data (Table 2). EHC assessment questionnaires were designed by the research team to assess EHC content validity, feasibility as a clinical intervention, and utility (cognitive benefits of EHC completion for EAWD- defined in this study as learning related to diabetes management- and communication benefits of EHC). EAWD questionnaires were written at a 6th grade reading level and administered verbally, to minimize potential literacy barriers for EAWD participants. Questionnaires were reviewed for content and clarity and revised prior to data collection by a diabetes researcher/clinician (Dr. Haw) and experts in EHC and/or qualitative/mixed methods research (Dr. Kimble, Dr. Martyn).

Table 2. **Data Collection Techniques by Study Aim**

<table>
<tr><th colspan="3">Aim I (Qualitative): Exploration of Emerging Adult and provider perspectives regarding Emerging Adult diabetes management and diabetes care visit interactions</th></tr>
<tr><th>Variable/Concept</th><th>Instrument</th><th>Description of items</th></tr>
<tr><td>Emerging Adult Demographics</td><td>Questionnaire</td><td>Age, gender, race, ethnicity, HbAlc, diabetes type/duration, diabetes medications, health insurance status, healthcare utilization, work/education status, living situation</td></tr>
<tr><td>Perspectives regarding diabetes self-management influences and current and desired healthcare visit communication for Emerging Adult diabetes management</td><td>Semi-structured focus groups and interviews</td><td>Semi-structured focus group/interview questions guided by the following topics:
1) What and who influences Emerging Adult diabetes self-management
2) Current interactions with Provider/Emerging Adult at diabetes care visits, including information asked about and received at visits
3) Desired interactions and outcomes during diabetes care visit
4) How EHC could be useful as an intervention tool for diabetes management at visits, including topics to include in EHC for Emerging Adults (Providers only)</td></tr>
<tr><th colspan="3">Aim III (Quantitative): Event History Calendar Assessment</th></tr>
<tr><th>Variable/Concept</th><th>Instrument</th><th>Description</th></tr>
<tr><td>Content Validity</td><td>Questionnaire</td><td>One item Likert rating of relevancy of each EHC topic to diabetes care visit
One item Likert rating of clarity of each EHC topic (Emerging Adults only)</td></tr>
<tr><td>EHC Feasibility</td><td>Questionnaire</td><td>**Ease of use:**
1) Time to complete/review EHC
2) Likert ratings of ease of use:
a) Ease of completion
b) Feasibility for clinical use (Providers only)</td></tr>
<tr><td>EHC Clinical Utility</td><td>Questionnaire</td><td>**Cognitive benefits:**
Likert ratings of information learned during EHC completion (Emerging Adults only)
Communication benefits: Likert ratings of belief EHC would aid in:
1) Information sharing
2) Better decision making for diabetes management by provider
3) Better self-management guidance during diabetes care visit</td></tr>
</table>

Data Analysis: Focus Groups/Interviews- Data were analyzed following a six step process of data organization/preparation, initial review of data, coding, description, representation, and interpretation.[67] EAWD data and provider data were coded separately to examine EAWD and provider perspectives on EAWD diabetes self-management and diabetes visit interactions. A mixed approach concept and data driven content analysis was used in which a combination of both concept driven (or deductive) coding derived from focus group and interview question topics and data driven (or inductive) coding were used to code data.[73] The principal investigator coded transcripts and her advisor (Dr. Kimble) reviewed the coding process. MAXQDA (Berlin, Germany) software was used for qualitative data management. Descriptive statistical analyses for demographic data was performed for EAWD and providers. EHC Assessment- Descriptive statistical analyses, presented separately for EAWD and providers, were calculated for all calendar feasibility and utility items. Evidence for content validity was calculated for all content validity items as I-CVIs as described by Polit Beck, and Owens, presented separately for EAWD and providers.[71] Topics that fell below an I-CVI of .78 were identified for revision or elimination based on team review of the item analysis.

Qualitative Rigor: Qualitative rigor, or trustworthiness, of qualitative research includes the use of strategies to meet criteria for credibility, confirmability, dependability, and transferability.[74] In this study, measures to enhance qualitative rigor included reflexive note taking by the principal investigator, triangulation of investigators through review of data and coding schemas with the principal investigator's advisor (LK), triangulation of methods (interviews and focus groups with EAWD), triangulation of data source (EAWD and providers), and maintaining an audit trail of decision making processes.[74] Attempts to establish rapport and the trust of participants to promote credibility of results were made during interview and focus group introductions and by conveying appreciation for participants' opinions and expertise throughout the study. Presentation of the findings included frequent use of participants’ own voice throughout the results to directly illustrate themes identified from data analysis and enhance confirmability. Demographic data collected from EAWD and providers as well as description of the setting in which diabetes care was provided were used to create a richer description of participants to facilitate transferability of findings.[75]

Paper 1: Perceptions of Emerging Adults with Diabetes regarding Influences on Self-Management and Interactions with Diabetes Care Providers at Diabetes Care Visits

Authors: Rachel Wolf, Kristy Martyn, J Sonya Haw, Laura P. Kimble

Abstract

Aim: The purpose of this study was to investigate perspectives of emerging adults with diabetes (EAWD) regarding diabetes self-management influences and perceptions of current and desired interactions with their diabetes healthcare providers.

Background: Emerging adulthood is a transitional life stage of transition to full adulthood and adaption to adult roles and responsibilities. Diabetes may compound these challenges. EAWD represent a growing but understudied population of diabetes patients with needs that may differ from other adult diabetes patients.

Methods: Focus groups and interviews with EAWD from a public healthcare system were conducted to identify influences on self-management as well as perspective on current and desired interactions with diabetes providers.

Results: EAWD identified intrapersonal, interpersonal, and structural influences on diabetes self-management. Diabetes was perceived as psychological burden which conflicted with EAWD perceptions of young adulthood and which was complicated by busy lifestyles and multiple responsibilities requiring prioritization. Family was a primarily positive influence while lack of resources served as a barrier. Public healthcare services mitigated some resource barriers to care. EAWD often perceived diabetes care visits as standardized visits providing access to diabetes supplies but desired additional guidance tailored to their needs and lifestyle. EAWD valued positive, ongoing relationships with providers.

Conclusions: EAWD desire diabetes care and support that acknowledges unique life stage and self-management barriers. Peer support and provider ability to tailor management to address burden specific to EAWD and EAWD priorities may facilitate care and engagement at and between diabetes care visits.

Key words: Diabetes, emerging adults, self-management, communication

Perceptions of Emerging Adults with Diabetes regarding Influences on Self-Management and Interactions with Diabetes Care Providers at Diabetes Care Visits

Introduction

Emerging adulthood is a distinct developmental stage of transition from adolescence to full adulthood. Emerging adulthood (18 to 30 years) is characterized by demographic diversity and instability as young adults seek to become self-sufficient.[1] Emerging adults coping with managing a chronic disease such as diabetes confront additional life challenges, particularly for a disease which requires an extensive degree of ongoing self-management and health system engagement.[2] The prevalence of diabetes among children and young adults continues to increase, especially among minority youth. [3,4] It is estimated that the prevalence of type 2 diabetes among 10-19 year olds increased 31% from 2001 to 2009.[4] With this increasing number of youth with diabetes, more emerging adults will be living with diabetes as they navigate the challenges of this developmental life stage.

The period of young adulthood presents a critical time period for the development of lifelong habits of self-care behaviors that may prevent or delay long term complications associated with diabetes as well as reduce the cost of care for a population that will be living with, managing, and seeking to avoid and mitigate the potential complications of diabetes for many years. Diabetes research has traditionally occurred in the context of either pediatric or adult care. However, the American Diabetes Association recognizes a need for distinct research and evidence based guidelines to facilitate diabetes care for emerging adults with diabetes (EAWD).[5]

Research to date suggests diabetes outcomes are less than optimal for EAWD. Many EAWD do not achieve target HbA1c values, and engagement in self-care behaviors has been observed to be less than optimal among this population.[6,7] Poorer psychosocial outcomes such as diabetes related distress are higher among EAWD, and EAWD are more reactive to diabetes stressors as compared to older adults with diabetes.[5,8–10] EAWD are also less likely to engage in follow up care even though continuity of care has been associated with better diabetes outcomes.[11,12] For minority and socioeconomically diverse emerging adults, these health outcome disparities may be even more pronounced. For instance, minority and socioeconomically diverse EAWD are more likely to have poorer diabetes self-management, higher loss to follow-up and higher HbA1c after transition to adult care, and greater diabetes related distress.[13–15]

Gaining an understanding of challenges that EAWD confront as young adults being cared for within the adult care health system will allow tailoring of interventions and strategies to provide life context appropriate care and guidance to EAWD. While a growing but limited body of research has provided some insight into these challenges, a significant amount of EAWD research and intervention focuses on the transition from pediatric to adult care.[16–19] Less is known about EAWD needs within the adult care setting, particularly among minority and socioeconomically diverse and EAWD. Current research suggests that factors such as balancing life priorities and diabetes management, logistical barriers, degree of support, and quality of the relationship with healthcare providers may impact diabetes self-management and perceptions of adult healthcare services delivery among EAWD.[20–24]

EAWD from minority and socioeconomically diverse backgrounds may face different or additional barriers to diabetes self-management and quality diabetes care than their peers from non-diverse backgrounds. Further insight into the experiences of this particular subset of EAWD is necessary to improve diverse EAWD outcomes. The purpose of this study was to investigate the needs of diverse EAWD within the adult care health setting through exploration of the perspectives of EAWD in a public healthcare system in order to gain insight to better serve this population. In particular, the aims of this study were focused on investigating the perceptions of diverse EAWD regarding: 1) factors that influence their diabetes self-management 2) interactions with their adult diabetes care providers during diabetes appointments and 3) wants and needs for their diabetes care visits.

Research Design and Methods

Study Design and Participant Recruitment

The study used a qualitative descriptive design.[25] Study participants were recruited from a diabetes care center within an urban public hospital in Georgia. The diabetes care center at the hospital includes endocrinologists, diabetes nurses, podiatrists, dieticians, pharmacists, social workers, and diabetes educators that provide comprehensive diabetes care to almost 14,000 adults with diabetes each year. The study was approved by the institutional review board at Emory University and given administrative approval from the hospital system prior to study activities. In order to ensure that participants could speak to the adult care experience within this public care setting, recruitment was limited to patients having attended at least one appointment in either the hospital's diabetes care center or primary care clinic within the past year (365 days). A list of eligible participants was generated from electronic health system records from November 2018 to November 2019 based upon the following additional criteria: age 18-30 years and diagnosis of type 1 or type 2 diabetes. This list generated a total of 160 eligible patients. From this list, a manual review of patient records was used to exclude patients who did not speak English (n=8) or who had developmental delays (n=8) or acute psychosis (n=5) that would preclude study participation. Patients who had been diagnosed within the past year (n=21) were also excluded in order to focus on the ongoing experience of diabetes self-management as opposed to the experience of initial diagnosis.

Recruitment letters were sent to 118 eligible patients with a return card for patients to indicate interest or disinterest in study participation. The research team attempted to make follow up calls to all participants who did not respond to the letter invitation (n = 109). Additional recruitment occurred via flyers posted at the diabetes clinic and referrals by diabetes clinic staff. A total of 37 patients expressed interest in the study (35 from letters and follow-ups calls, 1 from clinic flyers, 1 from diabetes clinic staff referrals), and 36 were confirmed eligible for study participation. Confirmed eligible patients were contacted by phone to provide additional information about the study and to schedule interested participants for focus groups. If EAWD could not be scheduled for a focus group or preferred an individual interview, an individual interview was scheduled. EAWD received reminder letters immediately after being scheduled for a focus group or interview and reminder calls the day prior to their scheduled session.

Data Collection

Focus groups and interviews were held in a private classroom or diabetes clinic office at the hospital. Focus groups were held on weekdays mornings, weekday evenings, and weekends to maximize the number of interested participants able to attend a focus group session. Interviews were held at a time convenient for participants. After written consent was obtained, participants completed a brief questionnaire to collect information on demographics, diabetes status and treatment, and healthcare access. Focus groups began with a brief introduction, including an explanation of the purpose of the discussion and establishment of ground rules to ensure an orderly and robust discussion.[26] The focus group moderator/interviewer (RW) used a semi-structured interview guide to conduct discussions. Questions guiding the focus group discussions and interviews are listed in Table 1. A research assistant was present at all focus groups to assist with the consenting process and to serve as a note taker during discussions. All interviews and two focus groups were recorded. One focus group was not recorded due to moderator error. Light snacks and refreshments were provided during the discussions. All participants received $25 cash compensation at the end of the discussion for their time.

Data Analysis

Data analysis consisted of a six step process of data organization/preparation, initial review of data, coding, description, representation, and interpretation to guide data analysis.[27] In addition, a mixed approach concept and data driven content analysis was used to analyze focus groups and interviews in which a combination of both concept driven (or deductive) and data driven (or inductive) coding is used to code data.[28] Interviews and focus groups were transcribed verbatim from recordings. Recording transcripts (notes for the unrecorded focus group) were imported into MAXQDA 2020 software (Berlin, Germany). After an initial analysis of the transcripts, three conceptual topics of focus were derived from the data and the study aims: Factors Influencing Diabetes Self-Management, EAWD Perceptions of Interactions with Diabetes Care Providers During Appointments, and Wants and Needs for the Diabetes Care Visit (The Visit as it Could Be). Transcript text was then coded using a data driven approach to identify themes within this categorization framework. Following multiple data driven coding cycles, a case by topic matrix was created to aid in visualization and analysis of research findings. Memos, reflective notetaking, and concept mapping were used throughout the process to facilitate qualitative data analysis and transparency of analysis. Quantitative descriptive analysis of demographic data was conducted using SPSS 25 (Chicago, Il.).

Results

Description of the sample

A total of 33 interested participants were scheduled for either a focus group or an individual interview. One additional participant could not be scheduled due to scheduling conflicts, and two participants could not be reached to arrange an interview or focus group. Of those scheduled for a focus group or individual interview, 14 EAWD participated in the study. Two focus groups were held with EAWD with type 2 diabetes and one with EAWD with type 1 diabetes (four participants, five participants, and two participants, respectively). Three EAWD (one with type 1 diabetes, two with type 2 diabetes) participated in individual interviews. Mean duration of focus groups and interviews was 46 minutes and ranged from 41 minutes to 84 minutes duration.

Demographic data are summarized in Table 2. On average, participating EAWD were 27 years old and had been diagnosed with diabetes for 9 years. All participants were Black and two reported their ethnicity as Hispanic/Latino. The majority of participants had type 2 diabetes. Most were female, and most worked at least part-time. Only half of the participants knew their last HbA1c value. Among those who could report their HbA1c, the mean value was 9.1%, which is above the recommended target HbA1c of 7.0%.[29]

Qualitative Findings

During focus groups and interviews, EAWD described factors influencing diabetes self-management, their perceptions of their diabetes visits, and their wants and needs during their diabetes visits. Main themes identified from analysis of transcripts are listed in Table 3 and are described in narrative below.

Factors Influencing Diabetes Self-Management

Participant perceptions of factors influencing diabetes self-management were identified and categorized into intrapersonal factors, interpersonal factors, and structural factors.

A. Intrapersonal Factors Associated with Managing Diabetes

Diabetes Burden

At an intrapersonal level, EAWD consistently discussed how diabetes is emotionally burdensome and tiring. As one EAWD described, "*Diabetes is like a job. It's hard work*" (EAWD #2). Many acknowledged that diabetes is mostly self-managed and the daily requirements of monitoring glucose levels, eating healthy, and taking medications are fatiguing. Additionally, several EAWD noted that they struggled to decide between the pain of injections and finger sticks and the knowledge that they needed to take insulin or monitor glucose levels to properly care for their diabetes. One EAWD verbalized this finger stick fatigue by stating, "*I've been sick for five years now, that's very old. I'm like, I'm not pricking myself today*" (EAWD #7).

Being a Young Adult with a Diabetes Diagnosis

For many of the EAWD participants, it was also emotionally challenging to be a young adult who has received a diagnosis of chronic disease at such a young age. One participant stated, "*I'm young, but I got old people problems*" (EAWD #12). The experience of attending a clinic where one does not fit in was disconcerting. Not only did several EAWD mention feeling like they did not fit in as young adults attending a diabetes clinic with mostly older adults, but they described their negative reactions to seeing older adults in and outside of the clinic with complications such as limb amputation and retinopathy: "*It was like I don't want to be here, oh no. Especially when they came with missing limbs and stuff. It scared me just to see that- made me real uncomfortable to be there*" (EAWD #6).

Motivation for Engagement

Many EAWD described how intrapersonal perceptions lead to active engagement in self-management. For instance, while the thought of having an "*old person's*" disease and the fear of complications was an unpleasant reckoning for many, for those with type two diabetes, there was often a hope (or desire) that, as young adults, they might be able to change the progression of the disease and get off of medications, particularly insulin: "*Some people be like it will never go away, but you can manage it enough that you won't have to take any medications. But I be really wanting to get rid of it period*" (EAWD #5).

Fears of acute and chronic complications motivated management behaviors and were specifically mentioned by nine EAWD as motivation for engagement in or adjustment of self-management behaviors. In one focus group participants discussed how they self-adjusted insulin doses in preference of hyperglycemia over the fear of hypoglycemia. "*I don't take as much medicine as they tell me to take. They prescribe too much. I don't eat as much as they prescribe. My sugar would be too low if I took as much as they gave me"* (EAWD #4). In addition to medications self-adjustment, others mentioned experimenting with different diets, and nine participants indicated that they used online resources to research diabetes on their own and to learn about topics such as medication side effects, diet, and the interpretation of lab results. For two participants who appeared uniquely organized and self-directed, diabetes management was no longer viewed so much as a burden but as a necessary component of achieving other life goals: "*I'm a full-time student, I work, I don't have time to be in the* *hospital. When they want you to come to the hospital, sit here for 20 days. I can't do it. I will avoid it the best way I can. Oh, I fixed my blood sugar. Oh, I figured it out. Now you have a hospital bill. And then it was hard to get insurance as well. That's just another thing. You're messing up my credit for no results. I can't deal with it. No, nope*" (EAWD #11).

B. Interpersonal Social Challenges and Motivators of Diabetes Self-Management

In addition to intrapersonal factors impacting self-management, interpersonal factors such as daily activities and interpersonal relationships were described as influencing diabetes self-management.

Active, Busy Lives

EAWD described leading active, busy, and sometime unpredictable lives that influenced diabetes self-management. Work, in particular, was an influencing factor. All but four participants were working, and for all of these EAWD, work was a primary influence on diabetes self-management. Most EAWD felt that their jobs (fast food, childcare, construction, trucking) made it difficult to engage in self-management tasks, although a few were able to manage diabetes well at work (Table 4). As one EAWD described, "*I don't have my meter with me [at work]. I'm at work all day, so it's very hard for me to check, so I leave it at home*" (EAWD #6). Several mentioned that the work environment was not conducive to healthy eating habits: "*Just eating like, there is so much good food. Especially where I work, my god, there is just so much good food*." (EAWD #9). For a few EAWD (n =3, all with type 1) the tasks of monitoring and regulating blood sugars made it difficult to maintain stable employment: "*Right now, I'm unemployed because it's hard for me to work…I may need to stay home today because my blood sugar is high, is extremely high. And I'm just not with working today with the highs and going to the bathroom. And I'm just not dealing with that today. Or I might be extremely low, either, or, you could end up in the hospital. Jobs do not understand that "Hey, I have to go to the emergency room today because I had a high. Yeah, I was there for eight hours. I'm sorry that emergency room so slow I missed my whole shift." But it is what it is. So after so many strikes, they're like "I can't save your job anymore, I have to let you* *go. I understand you are a diabetic but you're still in a work environment." They don't really understand it*" (EAWD #10).

While work dominated the conversations around activities and events that influenced diabetes self-management, some EAWD (n = 6) observed that social activities such as going out with friends or doing activities outside the house, were instances where healthy eating and monitoring could be thwarted by spontaneity, lack of healthy foods, or not having diabetes supplies available: "*It's just not fun. If I know I'm going out I have to make sure from the morning that everything is [organized]. Eat your breakfast, eat your lunch, eat your snacks. So when you miss something or you got to wait until two o'clock in the morning to eat something, you'll be good. It's like it's big!"* (EAWD #11). The importance of interacting with other EAWD and the emotional support derived from this shared experience was a sentiment echoed by each focus group as well as during an individual interview. During one focus group a participant observed: *"It was better to hear how a lot of other people feel because, oh, I'm not the only one feeling like this. I see a lot of people feeling how I feel"* (EAWD #6). Another participant nodded her head, responding, *"I feel like there should be more groups like this, more especially for people who can't come and say how they feel and they don't have to feel alone."* (EAWD #9).

Family as Primarily Positive Influence

Family (especially mothers) and significant others were the individuals who had the most impact on EAWD diabetes self-management. This impact was largely positive, with ten EAWD describing the importance of family support. Family was a motivator for healthy living; although two EAWD mentioned that eating healthy was difficult because they had to eat what other family members prepared, for many, family positively influenced eating habits. For instance, EAWD parents and caretakers wanted to ensure their family (especially children) had healthy eating habits. Wanting to be there for the people that they cared for was also an important motivator for engagement in diabetes self-management: "*I* *want to be there to do stuff with my girls...I want to be able to see my girls walk down the aisle. I want to be there every step. I want to be there because I didn't make it, I didn't walk down the aisle. I just want to see my girls grown and be successful in life. I got to get myself together*" (EAWD #14). For many, the visibility of diabetes complications among older family and community members enhanced perception of the need for self-care: "*So it like runs through the family. My dad had diabetes so he and my older sister has prediabetes, and I got diabetes type 2. That's what he had. So everybody be all on me about it because they don't want me to go through the things that he went through with the kidney failure and what else? He had kidney failure, fluid in his legs and all that stuff. Fluid, almost to the point of cutting his leg off*" (EAWD #12). Family and significant others also provided advise and emotional support for coping with diabetes on a daily basis. One EAWD observed, "*My mom makes it livable. She makes living with diabetes livable, honestly, because she's been there, of course, from the start. But more than I understand it, she understands it…So when it's hard for me to tell somebody no, that's not going to work because it just doesn't work like that with a diabetic. She's,* [letting others know] *'That ain't working for her because she's a diabetic just doesn't work in the diabetes world like that*'' (EAWD #10).

C. Structural Influences on Diabetes Self-Management

While EAWD spent less time discussing structural barriers to diabetes self-management, structural barriers were acknowledged during the conversations. Structural themes included both access to resources and their relationship with the healthcare system.

Access to Resources

Most EAWD (n = 11) mentioned access to resources as an influence on management. Several, for instance, mentioned the cost of medication and diabetes supplies (n = 5) or lack of affordable healthy foods (n=7). Others (n = 5) mentioned gaps in healthcare due to lack of or changes in health insurance coverage. While most EAWD acknowledged access to resources, particularly related to finances, few elaborated on these limitations. However, one EAWD did describe in more detail some of these challenges: ""*I mean, when you're talking about $200 a visit and then your insulin itself is like $400. And you have to take two. And you have to get blood sugar strips and... Like who can do that? Even with a 40 hour job a week you cannot do that and maintain a lifestyle. Just your roof over your head. I feel like people with diabetes have to apply for so much help and they don't offer it to us"* (EAWD #11).

Relationship to the Healthcare System

EAWD also expressed an ambivalence towards their healthcare system and its role in diabetes management. Even though insurance coverage and medication affordability were obstacles, EAWD were grateful for the access to health insurance coverage and affordable medications that the system provided them with: *"[The hospital] helped me out a lot. I can say that because my doctor visits are more expensive now because I stay in [another] county... I have to pay a copay of $20 and so $60 dollars. I can't pay the full amount of $400. I can't get a [hospital medication] card now because I don't stay in [the hospital] county. So sometimes when I can't afford it, they help me get my medications or get them for free or cheap*" (EAWD #7). At the same time, participants described feeling disadvantaged when others have access to private healthcare systems with better patient care experiences while they tacitly accepted the limitations within which they felt the public healthcare system operates: "*This is a big hospital, and this is also a teaching hospital, which is why I think we go through so many doctors. But at the same time…there has to be at least two consistent doctors here. And it's just not acceptable. Right?*" (EAWD #11)

EAWD Perceptions of Interactions with Diabetes Care Providers During Appointments

When asked to describe their diabetes visits, participants' responses lead to identification of three major themes regarding the nature of their diabetes visits: Routine nature of the visit, Value for time spent, and Tangibles and knowing where you stand.

Routine Nature of the Visit

Many EAWD feel that they hear the same messages at each diabetes care visit. One participant noted, *“[I am] pretty much waiting for them to tell me what I already know” (EAWD #4). Yet, as one individual observed, Yeah, it’s a lot by myself, but I don’t mind being independent. I have my refills, my numbers look good, then I’m good*” (EAWD #13). Another remarked, “*I’ve been coming to the diabetes center for four to five years, so it’s like the same thing, but mostly it is on me*” (EAWD #7).

Value for Time Spent

Participants discussed the value of the diabetes visit, particularly in relation to opportunity cost when their time is limited. Participants were not unanimous in their rating of the visit and their interaction with their diabetes care providers. A few participants felt that the visit was mostly helpful and were fairly content with their interactions with providers, many were somewhat ambivalent about the visit, and a few EAWD, particularly those with type 1 diabetes, were frustrated with their diabetes care overall. Almost all EAWD (n = 12) mentioned the wait time at visits to be the most unsatisfactory part of appointments. Given the amount of time that patients actually spent with provides, several patients felt that their time was not well spent, especially when they had other obligations, and what was actually accomplished at the visit could be accomplished in a more efficient, streamlined manner. One EAWD felt that the best part of the visit for her was, “*Going home, cause you are already in there for about 10 hours. They give you new medicine and just tell you the same thing over and over again”* (EAWD #9). Online appointments and office hours outside of the 9-5 work hours were suggested as alternatives to the routine. Six EAWD mentioned that they had either stopped coming to their diabetes appointments because of perceived inertia of care or came only for medication refills.

Tangibles and Knowing Where You Stand

When asked about their goals for the visit, participants indicated that they came for three main purposes 1) for diabetes supplies 2) to know where they stand and 3) to hear good news. For three EAWD, the only reason they came to the diabetes center was to obtain their diabetes supply refills. For the majority of EAWD, knowing their numbers and their progress in reducing their HbA1c was the primary goal for the visit. An EAWD described what she wanted from her visit: "*Nothing really. Just to be seen and see what's wrong with me, if something is wrong with me, see what's wrong with me, and that's it, and go home"* (EAWD #12). Many also acknowledged that they came to the visit hoping to hear good news or to avoid bad news: "*As long as I know things aren't getting worse, I'm okay*" (EAWD #4).

Wants and Needs for the Diabetes Care Visit (The Visit as it Could Be)

Participants discussed their thoughts regarding their needs and wants beyond their current expectations for diabetes visits. Three themes identified from discussions included: Need for Tailored Guidance, Beyond Content: Caring Relationship and Positivity, and Continuity and Communication between visits.

Need for Tailored Guidance

During the discussions, EAWD indicated that, while they may perceive the visit as an "in and out" experience and not necessarily as a time for acquiring new information and skills that can be applied to facilitate self-management practices at home, they need and appreciate personalized guidance for self-management that works for them and addresses their particular concerns (Table 5). Several EAWD (n = 3) observed that when they were first diagnosed, information was new and informative: "*The first time, they had a talk about it, so that was pretty helpful. They talked about diabetes and all the things that can happen having diabetes, so that was very helpful. After that they just do a reminder of what they talk about and all the things you're supposed to do to keep your body, keep your body right*" (EAWD #12). However, many (n = 12) felt that self-management advice was no longer useful. "*I think, yeah, they see you, tell you what you need to hear, but it don't really somewhat help sometimes in a ways…It feels like they're more of a cookie cutter type" (EAWD #6). Those with type 1 diabetes were particularly frustrated with lack of guidance: "It's like you're really here on your own, just figuring it out. You have the degree you went to medical school. I ain't make it there yet. So why am I* *doing all the work? And I come back and I say, yes, I changed my dosage. So I split this up into two, take one in the morning and one at night. I do this I do that or I won't take medicine at this time and stuff like that*" (EAWD #11). Some EAWD described receiving helpful self-management advice that was specific advice for their situation. For example, one participant noted that her nurse gave her useful tips on how to curtail snacking while also being prepared for low blood sugars and another found reviewing her meals and blood sugars with her nurse to identify associations between diet and blood sugars helpful for understanding dietary management.

Beyond Content: Caring Relationships and Positivity

Even more than the need for specific advice, all EAWD desired providers who conveyed that they care about individual patients. EAWD wanted to feel like they were not just numbers or part of the job. As one EAWD summarized: "*I want someone who going to listen to me, hear me out and understand me, where I'm coming from, and feel me, and just be there, just help me, help me overcome what my sickness and what I'm going through*" (EAWD #14). Caring was described in several forms. For some, this meant taking the time to allow EAWD to ask questions and to communicate in a way that patients could understand: "*I learn from looking. You can tell me anything but if I didn't visually see it I don't understand. Take your time with us we are paying to see you for more than 5 minutes. No rush. We need help*" (EAWD #3). For many, caring meant trying to understand the patient and his or her experience: "*It would be better if [providers] were diabetics. Because [providers are] reading the books. Knowledge is different than experience. So different. You can read about low blood sugar. You can tell the symptoms of low blood sugar. But when you're living with low blood sugar. It is not even half of what they put in a book…They're like "Oh, if your sugar's dropping, get something quickly." Yeah, I'm trying... I feel like if at least one person was a diabetic in there, it would make so much more sense. It would click. You would understand why we can't do this*" (EAWD #11). Caring relationships not only influenced EAWD perception of quality of care but enhanced the receptivity to provider messaging. As one individual observed, "*Receiving the information is easier from someone who seems like they care. If they don't care, it's like, should I listen to you? I mean I will but it's not as much- it's not as welcoming as something from someone that you prefer to be around*" (EAWD #13).

All EAWD wanted providers to frame messages in a positive perspective, and all felt that encouragement was important: "*Number one thing, please encourage us. PLEASE. That's the first thing. It's just the icing on the cake, encouraging us. Other than that, I don't have a second or third [request*]" (EAWD #9). Not only were EAWD eager for encouragement and acknowledgement of progress achieved, but they reported frustration when the message they received was framed in the negative (for instance, not meeting HbA1c goals, being at risk for losing a limb) especially when that message was not followed up with a solutions or advice for positive health outcomes: "*Good news [is when the doctor tells] them they have diabetes, but when you say they have diabetes, oh I can help you keep it low, or I can help you keep it at a good level. You give them bad news when you say, oh you have diabetes and that's it. You've got diabetes and tell them more bad things like your a1c is high, you've got to get this low. A doctor that gives the news away but don't help deliver it, like help with the process*" (EAWD #12).

Continuity and Communication between Visits

Several EAWD (n = 4) indicated that a caring relationship was easier to establish when they are able to consistently see the same provider during visits. Moreover, communication and access to providers between visits (n = 9) was described as fostering both the provider relationship and their ability to receive tailored guidance for self-management. Several EAWD observed that they could benefit from provider guidance for diabetes self-management (e.g. day-to-day decision making, medication concerns, sick day management) and were sometimes frustrated when they could not gain timely access to providers between visits: "*You've got to call them, they leave a message, and it takes them weeks to reply back and you are like, I don't even need the answer anymore. It's difficult to even talk to them so I don't even bother anymore, I just google it*" (EAWD #6). Conversely, several EAWD reflected on how important it was to them when providers called to check up on them: "*She sounds like she cares…You know, you're supposed to call in and give them your blood sugar. She's calling me. And I love that because it's like I'm not just a patient*" (EAWD #11). One focus group reflected upon the potential of regular phone contacts with providers as motivation for better self-management, with one participant commenting "*Oh, okay since you asked, I'm going to drink more water today. Since you calling, now that you me feel better, I ain't going to drink that drink. I'm going to go eat this. Since you're calling, feel so concerned. Motivated me. I'm going to go drink these waters. That would be better-calling and checking on me*" (EAWD #5). [Everyone laughing and agreeing].

Discussion

The participants in this study of EAWD seeking diabetes care in a public healthcare system described a variety of intrapersonal, interpersonal, and structural factors impacting their diabetes self-management. The emotional burden of dealing with diabetes as a young adult was particularly salient and compounded by busy lives, competing priorities, and multiple responsibilities of emerging adulthood. In regards to their interactions with their diabetes care providers, while EAWD in this study often viewed access to diabetes supplies and awareness of their diabetes health status as key components of their diabetes visits, the desire for (individually tailored) informational and affective support from diabetes care providers manifested in discussion of EAWD needs during diabetes visits. The healthcare system for these EAWD served both as a facilitator and a barrier to these participants' diabetes self-management needs, providing access to needed care and supplies but not always leaving participants satisfied with the quality of their care.

The findings of this study support previous research that finds a significant level of psychosocial burden for EAWD.[9,30] Diabetes distress has been described as a negative emotional response to the demands and challenges associated with managing diabetes.[31] Diabetes distress has been found to correlate with self-care behaviors, and, importantly, EAWD may be not only report more stressors and diabetes distress relative to older adults, but they may also be less able to modify the psychosocial impact of diabetes stressors at the same time they are more likely to have poor glycemic control associated with psychosocial burden. [32] Prior studies also suggest that diabetes distress may be particularly high among socioeconomically diverse EAWD.[21]

Interpersonal relationships seem to be a potential source of resilience and motivation for EAWD in this study. This included both the role of family and the provider in supporting both self-management capacity and motivation. EAWD in this study overwhelming and adamantly reported the need for positivity and encouragement from their diabetes care providers as much as they prioritized the need for specific informational content, which suggests that affective support related to diabetes burden, as much as instrumental support, may be a vital component of diabetes care for EAWD. Although continuity of care may be more challenging depending on the organizational structure of the healthcare system, EAWD in this study view continuity of provider as a contributing component of productive and meaningful diabetes care. The importance of the EAWD-provider relationship from the perspective of EAWD has similarly been reported in other work seeking to understand the needs of a broader population of EAWD; the desire for connection, rapport, understanding and collaborative person-centered care have been identified as components of a productive EAWD-provider interaction.[20,23,33,34]

A significant finding emerging from focus group interactions in particular and echoed in individual interviews was the strong interest for further interaction with other EAWD. This may be especially important for EAWD who may have been diagnosed with type 2 diabetes as adults or EAWD who may not have had access to pediatric social experiences such as diabetes camps. These findings suggest that previously developed transition of care interventions that provide peer support for EAWD during transition of care may be beneficial when extended beyond the transition of care period.[35,36] The potential benefit of such interventions are further supported by the current finding among EAWD for a need for understanding as well as interaction with others who can relate to the diabetes experience, a need which has been echoed in other studies soliciting the perspective of EAWD in general. [21,37,38] Additional considerations for EAWD specific group activities and support include adaption of these activities to potentially busy schedules and financial barriers.

Like other EAWD, the EAWD in this study find that the activities and responsibilities associated with emerging adulthood and the added task of managing diabetes on a daily basis creates additional burden in the midst of multiple priorities.[22,23,37] However, the nature of these responsibilities may differ. For instance, college has been described as a challenge to diabetes management among younger populations of EAWD with type 1 diabetes.[22,39] In the current study, most participants had not or were not attending college and were slightly older on average. For these EAWD work was described as the predominant challenge to diabetes self-management activities. However, in another study of urban minority EAWD, the work environment was perceived as primarily supportive of diabetes self-management.[40] Perhaps because in the earlier study of urban EAWD, participants were slightly more educated, they may have had job opportunities which engendered more psychosocial/structural support and flexibility for diabetes self-management. In contrast, many participants in the current study held jobs in construction, fast food industry, and other industries which may provide less flexibility for diabetes management at work. The nature of the influence of work on diabetes management among diverse EAWD merits further investigation.

Regardless of the exact nature of the many responsibilities and activities among EAWD, this study contributes to a growing body of literature that support person-centered diabetes care for EAWD provided in a manner that adapts to the unique needs of EAWD.[22,23,37] Essential elements of a person-centered care approach encompassing empathy, respect, communication, shared decision making, individualized and holistic care, building therapeutic relationships, and a goal of meaningful living appear pertinent to the needs of EAWD as reflected by the views of EAWD in this study.[41] This study supports the idea that EAWD must perceive the personal value of a diabetes care visit to be worth the cost of overcoming obstacles to attend appointments. Specific, practical, actionable, and age appropriate guidance may enhance the perceived value of diabetes visits and increase likelihood of regular follow-up and monitoring to improve diabetes outcomes. Among this population of EAWD it may be important to provide guidance and medical management tailored to being a working adult and maintaining or obtaining employment while managing diabetes. Soliciting concerns about acute and long term complications (such as preventing hypoglycemia while avoiding hyperglycemia) and providing actionable information within the context of EAWD lives may help EAWD feel heard and provide hope for control in the midst of social and economic barriers that limit sense of agency. EAWD may benefit from interventions that ensure they have ways to connect with and reach diabetes care providers outside of the standard three to six month visit and have reliable access to timely advice and support. Findings from other research as well as this study suggest that many EAWD are already interested in and actively engaged with “instant access” technologies such as internet that provide ready access to information.[9,42,43]

While the study provided additional insight into the perceptions of EAWD regarding diabetes self-management challenges and diabetes care visits within a public hospital setting, the study had several limitations. The participants may not be representative of the full diversity of EAWD in public healthcare settings, especially since participation was limited by difficulties recruiting participants, especially male EAWD, EAWD with type 1 diabetes and younger EAWD. Although use of focus groups as a method of data collection was challenging in this study, the discussion and interactions within the groups contributed to the quality of data collection in working with these EAWD participants. Therefore, focus groups may be a desirable tool for additional research regarding EAWD diabetes care needs but with significant logistical challenges; despite multiple contacts with interested participants, flexible scheduling, and attempts to reschedule individuals unable to make their first appointment, ultimately only 42% of interested participated in the current study. Two factors that may have contributed to a lack of study participation were identified from the study itself: active and sometimes unpredictable lives as well as a lack of sense of connectedness to their diabetes healthcare system. Challenges associated with EAWD recruitment are not unique to the current study. [4,21,22,44,45] Future research among this EAWD population may also require additional incentives and barrier reduction to enable study participation.

Additional purposive sampling may have provided better insight for comparison among different subsets of EAWD within the public healthcare system. For instance, differences in the experiences of EAWD with type 1 diabetes and type 2 diabetes as well as those EAWD having transitioned from pediatric diabetes care systems versus those diagnosed as adults were not fully investigated. The significant influence of the contrast between these healthcare environments on perceptions of adult care may warrant additional investigation. Additionally, while the researchers attempted to encourage robust discussion and differing opinions during focus group discussions, focus group discussion could have been influenced by group dynamics that biased the discussion.

Conclusion

EAWD receiving diabetes care within a public hospital system identify multiple challenges to diabetes self-management that are compounded by life stage roles and socioeconomic barriers. Moreover, EAWD in this study expressed the need for diabetes management care and services that meet their needs as unique individuals and as young adults. While diabetes visits are perceived as an access point for diabetes supplies and monitoring of diabetes status, the EAWD in this study suggest that they benefit from additional opportunities for tailored guidance and affective support from providers as well as opportunities for social connection with other EAWD. This study lends further credence to the need for addressing psychosocial health among diverse EAWD. It also supports the need for interventions that enhance the perceived value of diabetes care for EAWD by providing holistic, flexible, on demand, and individualized diabetes management responsive to the life priorities of emerging adults. Recognizing and addressing the unique needs of EAWD allows opportunity to improve diabetes outcomes for these young adults across their lifespan.

HIGHLIGHTS

- Emerging adults with diabetes (EAWD) desire timely and tailored diabetes care and guidance specific to their needs as young adults, which may include balancing self-management with work, active lives, social roles, and limited resources
- Given a high level of burden and psychosocial distress associated with managing diabetes while navigating life as young adults, EAWD perceive affective support from providers to be valuable components of diabetes care
- EAWD may benefit from opportunities to engage with other EAWD who can offer support and understanding

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Table 1. Focus Group/Interview Questions

What advice do hear from your doctors and nurses about what you need to do to manage diabetes?

What influences how you are doing managing diabetes?
- What makes it harder to manage diabetes?
- What makes it easier to manage diabetes?

What is your typical visit to your diabetes doctor and nurse like?
- What do your doctors/nurses do? What information do they share?
- What information do you share/what questions do you ask?

What do you want to accomplish at the visit?

What are the most helpful things about your diabetes care appointments?

What are the least helpful things about your diabetes care appointments?

In an ideal visit, what would you want to happen at your diabetes care appointments?
- What would your doctors/nurses do or what information would they share?
- What information would you share with your doctors/nurses?

Table 2. Participant Demographics (n = 14)

Characteristic	**Mean (SD) or n (%)**
Age, years	26.5 (3.23)
Sex	
Female	12 (85.7%)
Male	2 (14.3%)
Race/Ethnicity	
Black, Non-Hispanic/Latino	12 (85.7%)
Black, Hispanic/Latino	2 (14.3%)
Diabetes Type	
Type 1	3 (21.4%)
Type 2	11 (78.6%)
Duration of Diabetes, years	8.9 (7.3)
Last HbA1c, % +	9.1 (1.63)
Diabetes Medications/Equipment	
Oral Medications Only	2 (14.3%)
Oral Medications + Insulin	4 (28.6%)
Insulin Only	6 (42.9%)
Oral Medications + Insulin + GLP	2 (14.3%)
CGM	1 (7.1%)
Pump	0 (0.0%)
Employment Status	
Employed Full-Time	4 (28.6%)
Employed Part-Time	6 (42.9%)
Unemployed	4 (28.6%)
Educational Status	
Some High School	3 (21.4%)
High School/GED	4 (28.6%)
Some College	4 (28.6%)
Associate or Bachelor’s Degree	3 (21.4%)
Attending School	
No	12 (85.7%)
Part-Time	1 (7.1%)
Full-Time	1 (7.1%)
Living Situation ++	
Live with Children	4 (28.6%)
Live with Partner/Spouse	6 (42.9%)
Live with Other Relatives	6 (42.9%)
Live with Roommate(s)	1 (7.1%)
Marital Status	
Married	3 (21.4%)
Single	11 (78.6%)

Have Children	
Yes	3 (21.4%)
No	11 (78.6%)
Health Insurance	
Yes	6 (42.9%)
No	8 (57.1%)
Healthcare Usage in Past Year	
Routine Diabetes Clinic Visits	3.7 (3.12)
ER or Urgent Care for Hypo/Hyperglycemia	1.8 (2.89)
Hospitalized for Hypo/Hyperglycemia	1.6 (2.82)
Rating of Current Satisfaction with Diabetes	
Very Happy	0 (0.0%)
Somewhat Happy	6 (42.9%)
Somewhat Unhappy	6 (42.9%)
Very Unhappy	2 (14.3%)

Notes: SD = Standard deviation

+ n = 7; Seven participants reported not knowing their HbA1c

++ Could select multiple options

Table 3. Themes Identified for Each Topic of Focus

Topic of Focus	Identified Themes
Factors Influencing Diabetes Self-Management	Intrapersonal Factors • Diabetes Burden • Being a Young Adult with Diabetes • Motivation for Engagement Interpersonal Factors • Active, Busy Lives • Family as Primarily Positive Influence Structural Factors • Access to Resources • Relationship to the Healthcare System
Emerging Adult Interactions with Diabetes Care Providers During Diabetes Appointments	Routine Nature of the Visit Value for Time Spent Tangibles and Knowing Where You Stand
Wants and Needs for Diabetes Care Visits	Need for Tailored Guidance Beyond Content Continuity and Communication between Visits

Table 4. Ways in Which Work Environment Influences Diabetes Management

Challenges of the Work Environment	Successfully Navigating the Work Environment
• No time to eat regular meal • Forget self-management tasks • Unhealthy food choices • Lack of energy and time after work for meal planning/exercise • Avoid monitoring for fear of discrimination/job loss • Inability to obtain/maintain employment • Working while sick	• Planning meals ahead of time • Monitoring glucose as a means to avoid medical emergency at work • Self-advocacy to negotiate self-management and employer understanding • Working in a “healthy lifestyle” promoting work environment

Table 5. Type of Individualized Advice Desired

Glucose regulation (n = 11)	I don't take as much medicine as they tell me to take. They prescribe too much. I don't eat as much as they prescribe. My sugar would be too low if I took as much as they gave me. [All agree] (EAWD #3) I do not get it. My meds don't work I get the shakes when I don't take my insulin, I'm fine. It's when I take it, I feel funny. [All agree] (EAWD #1)
Advice for healthy eating (n = 7)	I need them to be relatable and logical like let's just be real. A person eats differently than their grandma. And because most of your patients are elderly people you guys are... Type 2 too. I need you guys to be like "Oh, we haves some type 1's in the clinic. Oh, we have some younger type 1's in the clinic who do more things." Because old people can sit here and say "Oh, I'm going to eat chicken on Sunday fish on Friday." We don't know what we're going to eat until we're about to cook. (EAWD #11) Nutritionists show portions, but that isn't going to keep me from being hungry (EAWD #3)
Need for progress/solutions (n = 5)	It's just like give me results. I can't keep coming here with no result. (EAWD #11) I really want them to help me to improve on getting myself together, questioning me or me questioning them to see what they can do or what I can do to better myself, to get my diabetes under control (EAWD #14)
Weight loss/exercise (n = 5)	See, that's the type of thing I need to know. What am I gonna do if I want to go for a run at 4:00am in the morning? (EAWD #10)
Addressing complications/ physical problems (n = 4)+	They must understand that on top of my diabetes that I have gastroparesis now. If they would talk to someone who understands gastroparesis straight on, then they probably would understand it a little more. But I have to ask first and I'm like with having gastroparesis first all you have to eat in very, very small amounts…So as a person I'm not one to eat three full meals a day. Living with the gastroparesis it's just not happening. I may eat one to two meals a day, but a lot of it is snacking. (EAWD #10)

Notes: + 3 with type 1, 1 with type 2

Paper 2: Diabetes Care Provider Perceptions Regarding Emerging Adult Diabetes Self-Management Influences and Patient Provider Visit Interactions

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Abstract

Aim: The purpose of this study was to investigate perspectives of diabetes care providers (providers) regarding their interaction with emerging adults with diabetes (EAWD) and their understanding of self-management influences among EAWD.

Background: As the number of adolescents and emerging adults with diabetes increases, providers are caring for more EAWD in adult healthcare settings. EAWD represent a unique subset of adults with diabetes. A better understanding of the needs of EAWD and their providers is required to improve EAWD diabetes outcomes.

Methods: Interviews with endocrinologists and diabetes nurses from a public healthcare system were conducted to identify provider perspectives regarding influences on EAWD self-management as well as provider perspectives on their interactions with EAWD during diabetes care visits.

Results: Providers report lower engagement among EAWD regarding diabetes management at and between diabetes care visits. Providers identified interacting intrapersonal, interpersonal, and structural barriers to EAWD diabetes self-management and the need for additional information from EAWD at visits to facilitate provider decision making and guidance for EAWD. Providers frequently described their role providing self-management guidance and the use of multiple strategies to support EAWD self-management.

Conclusions: Interventions may be needed to facilitate EAWD engagement in diabetes care and optimal EAWD-provider communication for diabetes management. Strategies may include focus on emotional burden related to EAWD life stage goals and priorities as well as identification of healthcare organization level resources for provider care of EAWD and the identification of effective self-management guidance strategies during diabetes care visits.

Key words: Diabetes, emerging adults, self-management, diabetes care providers

Diabetes Care Provider Perceptions Regarding Emerging Adult Diabetes Self-Management Influences and Patient Provider Visit Interactions

Introduction

As the prevalence of diabetes among adolescents and young adults grows, adult diabetes care providers are seeing an increasing number of younger patients with diabetes.[1] In recent years, estimates have suggested an incidence per year of 452,000 for adults age 18-44 and 210,000 for youth < 20 years.[2,3] Although older adults still represent the majority of diabetes patients seen by providers in adult diabetes care, healthcare providers need to adapt medical decision making and patient guidance to care for this younger emerging adult population (18-30 year olds), especially given that young adults may have different needs than older adults with diabetes.[4]

Emerging adulthood is a developmentally distinct period in life during which individuals may be learning to manage and cope with diabetes at the same time that they are transitioning from adolescence to the independence and responsibilities of full adulthood, including navigating the tasks of identity exploration, establishing gainful employment, and forming adult relationships and family units.[5] In addition, emerging adults with diabetes (EAWD) must engage in daily diabetes management activities that require a substantial amount of time, engagement and resources.[6] These tasks include taking medications as prescribed, engaging in decision making around healthy eating habits, exercising regularly, monitoring blood sugars-sometimes upwards of four times a day, and attending diabetes care appointments on a regular basis.

Previous research indicates that many EAWD do not met glycemic goals and that their engagement in self-management tasks is less than optimal. [7–11] Only 14% of 18-25 year olds with type 1 diabetes are estimated to meet their target HbA1c. While fewer data exist regarding outcomes for type 2 diabetes, the SEARCH study of youth and young adults reported poor control among 50% of youth over 18 years.[12] Likewise, EAWD patterns of access within the healthcare system suggest room for improvement in diabetes management interventions; younger adults age 18-44 years with diabetes have the highest rates of emergency room visits and hospitalization for hyperglycemic crisis, and data suggest lower rates of attendance at diabetes care appointments among EAWD.[8,13,14]

In spite of these challenges, emerging adulthood offers opportunity for development of lifelong habits promoting positive diabetes self-management and early interventions that may ameliorate the complications of diabetes. In order to take advantage of this opportunity, practices and policies regarding EAWD diabetes care and management need to be adapted to meet the needs of EAWD. Although clinicians and EAWD alike identify the importance of caring for EAWD within the context of this life stage in order to improve diabetes care and outcomes,[7,10] EAWD specific diabetes management considerations both within and outside the healthcare setting have yet to be fully elucidated.

Healthcare providers (providers) who care for EAWD serve an important role in a patient's diabetes management. Quality of patient provider communication has been shown to improve diabetes self-management, diabetes follow up, and health outcomes.[15–17] Prior research findings suggest that EAWD, too, value the patient provider interaction as important to their diabetes self-management.[18,19] As a key member of the EAWD healthcare, diabetes care providers offer valuable insight to optimize diabetes care specific to the needs of EAWD. Moreover, the perspective that diabetes care providers bring to the care environment informs the care that they provide to EAWD, and understanding of these perspectives may help align patient provider goals and improve patient provider communication.

However, few studies have examined the perceptions of diabetes providers within the adult healthcare system regarding their interactions with this younger population of individuals with diabetes.[20,21] The purpose of this study was to explore the perceptions of diabetes care providers working with EAWD in an outpatient public healthcare care setting to gain insight into how provider and EAWD needs can be better addressed to improve EAWD diabetes care management. In particular, this study focused on provider perceptions of factors influencing EAWD diabetes self-management and their interactions with EAWD during diabetes care visits.

Research Design and Methods

Study Design and Participant Recruitment

The study was conducted using a qualitative descriptive design.[22] All research activities were approved by Emory University Institutional Review Board, and administrative approval was obtained from the hospital system in which participants were employed. Healthcare providers were recruited via convenience sampling from a diabetes care center in metro Atlanta, GA that provides comprehensive diabetes care to patients within a public healthcare system. To be eligible for the study, a provider had to be an endocrinologist, nurse provider, or diabetes nurse educator and had to provide outpatient diabetes care to EAWD. Recruitment strategies were based upon the advice of the diabetes center head nurse and SH, a research team member on staff at the diabetes center. Nurse providers were invited to participate during a group informational session with the principal investigator (RW). Endocrinologists and nurse diabetes educators were invited via e-mail contact with the principal investigator.

Data Collection

A semi-structured interview guide was developed for interviews. Questions included in the guide are listed in Table 1. Participants completed a brief demographic questionnaire prior to the interview. Interviews were conducted between October 2019 and January 2020 on the hospital campus. After written informed consent was obtained from participants, interviews were held in person in participants' private offices, audio recorded and transcribed verbatim. Participants were assigned number identifiers for the purpose of data presentation. While the study was not specifically designed to examine differences in the views of nurses and endocrinologists, participants were also identified by provider type as nurses and endocrinologists served somewhat different roles at the diabetes center.

Data Analysis

Data analysis consisted of a six step process of data organization/preparation, initial review of data, coding, description, representation, and interpretation.[23] In addition, both concept driven (or deductive) and data driven (or inductive) coding were used to analyze interviews.[24] Data were transcribed and reviewed and then imported into MAXQDA 2020 software (Berlin, Germany). After the initial analysis of transcripts, using a deductive approach,[25] conceptual categories derived from interview questions were used to organize transcript data for additional analysis. Multiple cycles of inductive, data driven coding were used to identify themes within these conceptual topics and to allow for identification of additional themes regarding provider perceptions of their interactions with EAWD. Coding was performed by RW. Codes and coding strategies were then presented to a second researcher (LK) for secondary review. Memos, concept mapping, and reflective notetaking were used to facilitate qualitative data analysis and transparency of analysis.

Results

Description of the Sample

A total of eleven providers were invited to participate in interviews, and all eleven participated. Participants included five nurses who each provide care to a designated caseload of patients receiving care at the diabetes center as well as four endocrinologists who see patients at the clinic. Two diabetes nurses who provide both group outpatient diabetes education classes and in-patient diabetes education to patients also participated in the study. Interviews lasted a mean of 45 minutes (range of 20 minutes to 83 minutes, standard deviation of 17.8 minutes). Demographic data collected from the self-report questionnaire completed at the time of the interview are presented in Table 2.

Qualitative Findings

Data analysis revealed that providers' discussions of their interactions with EAWD and their perceptions of EAWD included five major topics of focus: 1) provider perspective on EAWD engagement in diabetes care 2) factors influencing EAWD engagement in self-management 3) perceptions of EAWD and provider goals at visits 4) visit productivity 5) and strategies for engaging EAWD. Topics of focus and their associated themes and subthemes are summarized in Table 3 and described below.

1. Provider Perspective on Quality of EAWD Engagement in Diabetes Care

Engagement was an overriding theme among providers when discussing EAWD interactions and provider perceptions of EAWD. Most providers (n = 9) felt that level of engagement in diabetes management often distinguished EAWD patients from their older patients with diabetes. Diabetes clinic nurses, especially, observed that the EAWD they care for may not be as engaged in managing diabetes during visit or taking ownership for self-management outside of the visit: "*I feel like my young adult patients are more in a hurry to get in and out of here. I don't know if it's apathy or sometimes if they don't understand how important it is. But I feel like sometimes the older patients care a little bit more. The younger patients are always on their phone and gives yes and no answers instead of big explanations*" (Nurse #3). Yet, providers valued the role of EAWD in diabetes management: "*It's something that if you don't do your seven behaviors which includes taking your medicine, exercising, eating the proper portions of foods and so forth, then you won't have a good outcome. That's it*" (Nurse #5). EAWD recognition of their self-management role was vital, "*So it's a lot of things that they have to do, like I said take ownership, you've got to do some things in order for us to be able to help you*" (Nurse #1).

2. Influences on EAWD Engagement in Self-Management

Providers reported intrapersonal, interpersonal, and structural factors that they perceived to influence EAWD self-management. Intrapersonal influences included a) perception of risk as a young adult and b) emotional health and burden. Interpersonal influences included a) busy live and multiple responsibilities and b) EAWD social norms and activities. Structural barriers included a) healthcare adulting and a new environment b) technology and c) access to resources.

A. Intrapersonal Influences

a) Perception of Risk as a Young Adult

Providers (n = 7) often thought that having a chronic disease did not resonate with EAWD schema of young adulthood, and this influenced their perception of the risk for diabetes complications. For instance, many observed that EAWD experiences or, more often, lack of experience with complications from diabetes influenced self-management behaviors: "*I think sometimes with the older adults- and it really can vary so much because some of the younger adults are interested and wanting to know how to manage their diabetes. But I guess I'm thinking a lot of times because the older adults have had it for a while and they are more mature thinking and they are really and perhaps they've seen or experienced complications in some cases and they are wanting to prevent it from getting worse. Whereas the younger adults- in some cases they don't take it as seriously as I wish they did. In some cases they may know about complications but they are thinking it is not going to happen to me type thing. So I think that's the biggest difference* (Nurse #6). Several also observed that their EAWD patients fail to make connections between how their behaviors increase risk for diabetes complications: "*Some of them will come every 3 months but if you are still eating excessive carbs, drinking a lot of sodas, how can you expect a change in your blood sugars or A1c. You can't just take the medicine and think that' going to change everything. It's not a fix for everything- you have to watch what you are eating, you have to exercise, you have to take your medicine. They don't see the big picture*" (Nurse #2).

b) Emotional Health and Burden

Diabetes fatigue and burden experienced by EAWD were also observed by providers as influencing EAWD self-management of diabetes. Not only did providers (n = 10) observe EAWD fatigue with the many challenges of managing diabetes on a daily basis (especially the pain and burden associated with checking glucose and giving injections), but they identified a frustration with the lack of agency for EAWD to either do what they need to do to manage diabetes or the lack of consistent positive results when patients try to manage diabetes. A provider described their view of what some EAWD experience: "*You're uncontrolled, and you go to the doctor, and they say you have to do this and this and if you don't have the means to implement that plan, I think you probably get more depressed and feel more helpless, like oh I can't do this. They want me to do more, it's just too much, I can't do it, so I won't do anything kind of thing...So I think there is that apathy slash diabetes distress*" (Endocrinologist #2). In addition, several providers (n = 5) observed that addressing underlying mental health diagnoses was paramount to understanding and addressing diabetes management: "*From day one when I started work here, that was something that I saw. That if the mental health is not being treated then the diabetes is never going to be treated until we get to the mental health together. And if the patients are on their medications and their medications are working, then they're going to come in and they're going to be more [in control]* (Nurse #5).

B. Interpersonal Influences

a) Busy Lives and Multiple Responsibilities

All providers observed that EAWD struggle to balance multiple roles and responsibilities while managing diabetes. Diabetes may not be a priority and it may be difficult to take the time to engage in diabetes management activities. One provider described the impact on daily self-management: "*A lot of people are faced with many different factors when they come here. So, it's not just diabetes that they have going on in their lives. So sometimes I feel like it takes the back burner of everything else that goes on in their life*" (Nurse #3). Another provider elaborated how EAWD responsibilities often prevent EAWD from engagement in optimal self-management choices such as healthy eating: "*It's hard when you have little kids and they want a lot of fast food. And you've got a single mom who is working. Fast food is easy, it's quick, and it feeds the family but it's not necessarily a healthy thing*" (Nurse #6). Likewise, showing up to appointments may also be difficult with less predictability and less flexibility: "*I believe the younger adults miss more appointments than the older adults - no question. But imagine that you* *are the mother of two kids, and you have been given an appointment given three months ahead of time. What happens if your kids are sick or you have so many things going on? The older adults usually put that in the schedule, and they don't have many other things to do, or just work and it's easier to treat them. I think the younger adults have significantly more challenges than the older adult*" (Endocrinologist #4).

Specifically, providers most often mentioned work (n = 11) and school (n = 7) responsibilities as roles influencing EAWD diabetes self-management. All providers observed that work was a significant influence on diabetes management among EAWD and that the types of jobs in which their EAWD are often employed (i.e. fast food, servers, construction) are often not jobs that allow patients the resources or flexibility to engage in diabetes management tasks in a timely manner. For instance, a nurse noted that in regard to work, "*They don't really have the time to take and check the sugar and take their medicine or take their insulin or whatever. They don't have that, and that factor is not that important to them. It's getting the job and you know, it's not important right then and there*" (Nurse #5).

b) EAWD Social Norms and Activities

Providers (n = 8) also described how social norms and activities impacted diabetes management for their EAWD patients. One provider described the importance of recognizing the challenges of developmental tasks associated with young adulthood, regardless of diabetes "*So what is the plan? What are they doing. Are they working? Are they pursuing education? What is going on and how do you manage diabetes in the context of figuring out your new life- transitioning from being a child to being and adult- it's tough*" (Endocrinologist #3). A nurse described challenges for EAWD engaging in normal young adult social activities, "*They want to, especially with the younger people, they want to be like everyone else. They don't want to have to do things different. They want to eat the same. They want to hang out with their friends. They don't want to take shots*" (Nurse #6). A few providers reflected upon EAWD perceptions of body image/weight (n = 2) as an important social factor influencing EAWD self-management behaviors: *"[EAWD] are more prone to do exercise although they are less likely to follow good nutrition support. Now a lot of young people are very concerned about their weight, so they keep their weight down or at least try not to gain much weight*" (Endocrinologist #4). A few providers (n = 3) also observed that EAWD often lead more physically active lifestyles and be more likely to participate in planned physical activity, although they also noted that work and other obligations may conversely serve as barriers to exercise goals for EAWD.

C. Structural Influences

a) Healthcare Adulting and a New Environment

Adulting as it pertains to healthcare, or navigating the typical tasks associated with being an adult patient in an adult healthcare system, was observed to be a barrier for EAWD. Several providers (n = 5) acknowledge the role that entering (or transitioning to) the adult healthcare system for the first time may have on EAWD. Often this is in the context of newly acquired independence, and EAWD may have anxiety related to not knowing their role as an adult patient. For instance, providers noted that EAWD patients may be unfamiliar with navigating the healthcare system, including the tasks of managing health insurance or obtaining medication refills. One endocrinologist observed, "*Some of the responsibilities, I think older patients understand things about how the systems work- insurance, Medicare, Medicaid, those type of things, how to acquire things- money, finances, that type of thing. A lot of our younger patients, I'm not sure they have a great understanding of just practical aspect of how medical care would work and I think that's a difference because it does impact things. Having the ability to know what you could get so if you could qualify for insurance, if you could qualify for aid, and having that thought in your mind… Adults are faced with that on a daily basis*" (Endocrinologist #3).

b) Technology

Though EAWD may be less familiar with adult healthcare, a few providers (n = 3) felt that their EAWD were often more aware of technology such as insulin pumps and continuous glucose monitoring and more interested in using technology to support self-management. While six providers (especially diabetes center nurses) mentioned EAWD cell phone use as a distraction preventing full engagement during visits, three providers also felt that EAWD adeptness with technology was an aspect of self-management engagement more common among their younger adults: "*They are very interested, the younger adults, in how to treat diabetes with technology, the use of CGM (continuous glucose monitoring), about 30% of patients with type 1 diabetes are now on insulin pumps, which is not very common in the older adults. I think younger adults are more prone to technology compared to the older adults*" (Endocrinologist #4).

c) Access to Resources

All providers perceived lack of access to resources to be a major barrier for many of their EAWD patients, although as several providers noted, many of these barriers are not unique to EAWD, but rather to the community served by the hospital system. Providers noted that their EAWD often confront multiple financial challenges limiting EAWD's ability to afford healthy foods, health insurance, stable housing, and stable supplies of medications and blood sugar monitoring equipment.

Limited resources complicated diabetes management for EAWD. Several providers (n = 3) detailed how financial priorities and physical accessibility also complicate diabetes self-management, "*Are you having to pay your rent and get your medicines, or are you having to pay your rent and get food so you can't pick up your medicines because the medications are too expensive? Finance is another thing I like to know what's going on because sometimes I have a patient that's getting all their medications at Walmart. Well, some of those medications you can get at Public for free. Well, some of those patients, I don't live near a Publix, so I have to get them at the Walmart*" (Nurse #1).

Likewise, the lack of access to the full range of therapeutics due to cost and insurance barriers (n = 8) impeded the ability of providers to offer options for tailored to the needs and preferences of active and socially conscious young adults: "*They get tired of sticking their finger. Unfortunately, the Freestyle*

Libre or Dexcom are just unaffordable for so many people, but I think compliance would be so much better if some of the tools for diabetes were less expensive, but that's a whole other issue. If everybody could get that Freestyle Libre and check their blood sugar without checking their finger, or if it was just more affordable, I think they would do it all the time. Like the patient I had just yesterday who wanted pens, he said I'll take it if I can get a pen" (Nurse #6).

3. Goals for Diabetes Care Visits

Two themes related to providers perceptions of goals for diabetes care visits were identified. Those included a) provider perceptions of EAWD goals and b) progress and a sense of accomplishment as shared goals.

A. Provider Perception of EAWD Goals

The majority of providers (n = 10) felt that the goal of many EAWD was to get in and out of the clinic quickly and return to their normal activities. Most providers (n = 8) felt that patients come primarily for supplies, which caused frustration for providers hoping to improve care by assessing and making adjustments based on the information they get from lab data and information from patients regarding complications (i.e. hyper and hypoglycemia) and barriers to self-management: "*It's not uncommon that you don't feel that you have really touched them in the way they are going to improve diabetes control because they are just there because they have an appointment. They just need the insulin, the prescription, but they are not really prone to listen to you, and you know that from the beginning*" (Endocrinologist #4).

B. Progress and Sense of Accomplishment as a Shared Goal

Providers indicated they perceive that patients (n = 7) and providers (n = 8) often desire progress in diabetes management, whether through meeting HbA1c target goals, observing incremental progress towards those goals at the time of the visit, or taking enabling steps towards achieving progress during the visit. When discussing interactions at visits, many providers (n = 5) indicated that both providers and patients may feel frustrated by lack of progress and stagnation in managing diabetes at and between visits. Several providers described how they managed visits to ensure a sense of accomplishment from visits. For instance, calling patients prior to appointments allowed nurses to adjust visits for maximum productivity: "*I may tell them let's reschedule that appointment to a later time when you've had a chance to take your medicines and get things a little in control before you come back so they won't be frustrated that you left here two weeks ago with a 400 blood sugar, you still haven't picked up your medicines and when you come in 4 weeks it's still going to be 400 so you won't be frustrated, I won't be frustrated, let's make it in another 4 weeks so after you've picked up your medicines we can see how things are at that time*" (Nurse #1).

4. Visit Productivity

Providers described visit productivity related to three themes. Two themes were related to level of EAWD engagement at visits: a) showing up matters and b) showing up is not enough. A third theme described by providers related to visit productivity was c) relationships and understanding matter.

A. Showing Up Matters

Several providers (n = 6) commented on the importance and significance of EAWD attending appointments, acknowledging that for EAWD showing up is often more difficult and requires additional motivation and organization. However, when their EAWD show up providers have opportunities to tailor medical management for patients and help them navigate the healthcare system. One provider observed, "*So most patients improve diabetes care based on education, treatment, but only if they come to the clinic. They don't show up, there is no way that we can help them. Right now, we have 12 different medications with different mechanisms of action…so we have treatments that can be tailored for individual patients based on what they need, what they want, access to care, if they have insurance or not*" (Endocrinologist #4), and a nurse elaborated, "*It's the first step. You have the resources, not only are you just going by symptoms of how you feel, but now we have numbers because we are watching* *your A1c, we are looking at your blood sugars. The doctors might draw more labs. So you are just getting a little bit better care*" (Nurse #7).

B. Showing Up is Not Enough

Nevertheless, providers also felt that showing up was important but not enough to maximize the role of diabetes care visits for EAWD diabetes management. Providers described visits as an opportunity and necessary for engaging patients in assessment for both medical decision making and patient guidance.

a) Need for Hard Data from EAWD

For all providers, assessment data (whether collected from the lab, data from the patients' blood glucose meter, or data self-reported from the patient his or herself) allowed the provider to make informed medical decisions and engage in problem solving for patient self-management. All diabetes center nurses observed that EAWD may not bring their meters and blood sugar logs: "*They may come in with no numbers to show me and then they'd tell me about the times when they're experiencing things, but if you don't have anything to show us then the doctor doesn't have a way to, an accurate way to adjust your medications. So I kind of feel like sometime it's not pointless, but it's not good that you don't come in with any information for us because how can we help you if you're not keeping the record of your numbers*?" (Nurse #3).

b) Need for Active Engagement from EAWD

For the majority of providers (n = 9), the difference between a productive visit and less productive visit depended on the patient's level of engagement at the visit. When providers were asked, productive visits were frequently defined by level of patient engagement in addition to sense of progress. Less productive visits with EAWD were all defined by lack of active patient engagement. Active engagement included EAWD actively processing information and actively participating in the conversation. One provider described, "*I like it when I feel like I am not just talking at them but that they* *are actually involved in it and they are playing it back and figuring out ways of how they are going to balance it all out in their day to day life*" (Nurse #7). Even active resistance to change during a visit was appreciated over nonengagement: "*I think when patients are like okay, alright. Okay, fine. Like you tell them whatever, and they don't want to talk, or I'm okay even with arguing because that means you are somewhat engaged. I think a bad visit is when, alright, okay, nothing*" (Endocrinologist #2).

Providers (n = 8) often observed that EAWD did not voluntarily share information, though providers described the importance of querying patients for information to identify barriers, particularly those related to problems with glycemic control (n = 9): "*I need feedback in order to tell them what to do moving forward, how to make changes, how to improve. Without knowing where they stand, it's kind of hard to help them improve the situation*" (Nurse #4). The more accurate and granular the information, the more confident providers felt in being able to provide useful guidance. As one provider mused, "*Most of the smart phones now could- I had patients that are like, oh I don't eat meat and I'm like oh really? Yeah, I stopped eating meat. So what did you eat? And our nutritionist was great and where I got this idea, she asked to take pictures and showed me a picture and yes it was not meat, but it was all Mac & Cheese and not vegetables. So it's that kind of like, sure they tell you one thing but it's not really*" (Endocrinologist #2).

c) Relationships and Understanding Matter

Providers (n = 9) described the value of building a therapeutic relationship with their EAWD patients. Listening and hearing the patient were vital to addressing the anxieties, frustrations, and fears EAWD may bring to the visit. A therapeutic relationship meant understanding the individual's past experiences, present situation, and goals. Many expressed empathy for the challenges of living with diabetes or acknowledged the importance of learning from other EAWD who could relate to that experience: "*It's an interesting thing because sometimes you want to scold them, sometimes you want to hug them and make them understand that okay. I feel you. I know what you're going through*" (Nurse

#5). Several (n = 6) observed that EAWD often fear judgment and need providers to approach care in a non-judgmental manner.

Providers also noted that continuity (an ongoing relationship) with a provider furthers the relationship and allows providers to better individualize care, motivate patients, and make interactions more productive: "*And I think that really does help if you [the patient] are not retelling the story every single time, I think that's part of breaking that barrier because you have to repeat yourself every time- it's frustrating- you don't feel like you are getting anywhere." (Endocrinologist #3).* Diabetes center nurses too had started making phone calls between visits and reflected positively on this outreach: *"It's really been helping…They are very thankful, grateful that you did call them. They are appreciative. 'Oh, well thank you for calling me checking up on me'"* (Nurse #1).

5. Strategies for Engaging EAWD in Diabetes Management

In describing their interactions with EAWD and the information exchanges during visits, all providers reflected upon their role beyond the performance of standard visit procedures, especially that as a facilitator of patient self-management. Several different approaches were identified in providers' descriptions of their visits with EAWD. Table 4 summarizes the different strategies described by providers for engaging EAWD in self-management and presents exemplar quotes representing providers' use of these strategies. While most providers had distinct overall styles for approaching self-management guidance, most also described using a combination of strategies in their interactions with EAWD.

Discussion

In this exploration of the perceptions of diabetes care providers serving the needs of EAWD within a public healthcare setting, providers described a range of intrapersonal, interpersonal and structural factors that influence the self-management behaviors of this young adult population and which may act in synergy to challenge engagement in self-management. Providers thought that engagement in diabetes self-management itself often represents a distinguishing difference between EAWD and their older patients with diabetes. Emotional burden, multiple responsibilities such as work and school, and adapting to an adult healthcare setting were felt to be frequent barriers to EAWD self-management. Providers also viewed diabetes care visits with EAWD as an opportunity to improve EAWD diabetes management and to utilize strategies to identify and address barriers to self-management. Yet, providers acknowledge the need for active EAWD engagement and cultivating the patient-provider relationship in order to provide the most appropriate care for a particular EAWD patient during their diabetes care visits.

In a multi-level framework for engagement, patient engagement has been defined as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system…to improve health and health care,” (p.224).[26] In this study, providers described engagement at the patient level, in terms of EAWD participation in diabetes care activities and active participation in information processing and exchange at clinic visits with a view that these actions facilitate EAWD diabetes care and health outcomes. The perceptions of providers interviewed for this study support evidence regarding EAWD engagement and barriers to self-management described elsewhere. Evidence that EAWD may not be as engaged in daily diabetes self-management tasks or in regular attendance for routine diabetes care visits has been presented in prior surveys of EAWD but not necessarily corroborated by providers themselves, as indicated here.[9,11,14] This study suggests that providers perceive lack of engagement as a challenge especially pertinent to EAWD. Yet, importantly, providers observed that lack of active engagement may not be an entirely personal decision for EAWD confronting many social and structural factors that hinder engagement. Providers for younger lower income women with gestational diabetes identified a similar range of intrapersonal, interpersonal, and structural barriers, including work priorities, access to supplies, and lack of engagement and lack of motivation.[27] These providers observed that patient inability to effect change given these barriers may lead to further disengagement in care, a reflection likewise echoed by providers in this study. Importantly, the perceptions of providers in this study align in many respects to the views of EAWD regarding barriers to self-management indicating that providers have some degree of shared understanding of barriers to diabetes self-management as EAWD too have described how diabetes fatigue and burnout, lack of time, and multiple responsibilities can hinder self-management.[4,19,28,29]

Despite some shared understanding with EAWD of frequent barriers to self-management, the current study suggests that while diabetes providers recognize the role of effective bidirectional communication for EAWD diabetes management and the EAWD provider relationship in diabetes management, providers and EAWD may need additional resources and guidance to help facilitate effective communication that meets both EAWD and provider needs. Providers in this study relied upon information and data collected from patients to optimize EAWD care and needed contextualized and open communication. For EAWD too, a positive and trusting relationship with a healthcare provider and continuity of care are felt to be important to their diabetes management, yet they describe challenges engaging in open discussion with providers.[16,18,30,31] For instance, fear of judgement and a desire of EAWD to prioritize discussion of certain topics in their limited clinic time may indeed be influencing factors in information exchange.[30] Similarly, providers in this study and elsewhere reported feeling that diabetes patients may not always fully share information- either unintentionally or due to fear of judgement.[27,32]

In considering EAWD provider communication, providers felt that both patients and providers desired progress. However, it is important to acknowledge differences in patient and provider definitions of progress. While diabetes standards recommend tighter HbA1c goals among EAWD and providers in this study valued tighter HbA1c control among their EAWD,[33] EAWD report a desire or need to balance tight glycemic control and optimal diabetes self-management with competing life priorities such as school, work, and family.[19,34,35] For instance, providers may seek to evaluate and define progress based upon biometric outcomes and adhere to recommendations of tighter glycemic control for younger adults with an understanding that such adherence can prevent complications later. In contrast, EAWD report the need and desire to evaluate progress based upon more individualized goals and non-numerical standards adapted to their current life situation. [30] Aligning goals may have the potential benefit of improving attendance at routine care appointments, communication, and increased quality and effectiveness of diabetes management. “Person-centered care” has been distinguished from “patient-centered care” in that person-centered care recognizes individual goals of a meaningful life beyond the metrics of functional living.[36] While patient-centered care is now recognized as integral to diabetes care practices ranging from medication selection, glycemic targets, and diabetes education,[7,33,37,38] for EAWD especially, an expanded conceptualization of patient to person-centered may be particularly important, and whole person approaches such as life coaching may offer a useful approach for providers to facilitating such care.[39]

Some research indicates providers proffer self-management guidance as a component of routine diabetes care, although the extent of guidance may vary.[40] Providers in this study frequently described their role encouraging EAWD in diabetes self-management and gave additional insight into strategies that providers may use to engage their EAWD patients. Providers detailed offering not just informational support but also affective and cognitive support to their EAWD patients (through reframing and problem-solving strategies). Given the relationship of adaptive coping skills and outcomes among EAWD and the call for providers to work with EAWD to identify more individualized, short term motivators for realistic self-management practices, these strategies may be particularly appropriate communication strategies for self-management among EAWD.[41–43] Moreover, affective strategies such as reframing diabetes self-management may be especially useful given that EAWD report the need for positive encouragement from providers and experience a high psychosocial burden associated with diabetes.[9,10] Problem solving and adaptive coping strategies have been associated with better diabetes outcomes among EAWD, a population that may still be maturing in regards to executive function skills.[41,44,45] Understanding the relative importance of various EAWD tailored communication strategies including affective support, individualized collaborative problem solving, navigating care, and negotiated goal setting could serve as an additional framework to guide EAWD care, whether provided by an individual or a multidisciplinary team.

Given some of the challenges identified by these providers in supporting the needs of EAWD during and between diabetes care visits, a flexible and multi-faceted approach may improve diabetes management and engagement between and during visits. For instance, flexible appointment times offering appointments within a short-term time frame and virtual or telephonic contact between in person visits could adapt to EAWD's less stable schedules. EAWD challenges in navigating an unfamiliar healthcare system and coping with limited resources may require additional support systems for navigating the healthcare system and accessing resources. In healthcare systems providing care to EAWD that may be further disadvantaged due to socioeconomic limitations, navigational support may be even more critical.[46]

However, challenges to EAWD care may extend to the resources both outside and within the clinic environment. Even interventions specifically designed for socioeconomically diverse EAWD acknowledge underestimation of the role of resource barriers to diabetes self-management. [47] While providers in this study were not specifically asked about barriers to caring for EAWD within the adult clinic, previous surveys of endocrinologists regarding EAWD suggest concerns regarding availability of resources for EAWD within adult care. Adult endocrinologists have identified a lack of needed resources such as mental health services, care coordination, and exercise physiologists relative to the perceived need for these services among EAWD, and pediatric endocrinologists express concern that a lack of resources and expertise working with young adults in adult care settings may hinder EAWD care.[20,21] The recognition of providers in the current study regarding the complex interactions between unmet resource needs and life challenges of socioeconomically diverse EAWD further emphasizes the need for creative solutions to address availability of resources tailored to EAWD circumstances and lifestyle. While this study offers a better understanding of the views of diabetes care providers working within public hospital comprehensive diabetes care facility regarding their EAWD patients, the findings may not represent the views of all diabetes care providers. Additionally, although prior literature suggests that the views of these providers are similar in respects to some of the views of EAWD regarding self-management challenges, the findings in this study represent only a partial perspective on EAWD diabetes management that requires additional follow up in other settings and among other stakeholders interacting with EAWD. These findings are limited to self-report and providers views may be influenced by particularly salient encounters with EAWD. Observation of EAWD provider interactions may be particularly useful to confirm and elaborate on the nature of provider interactions with EAWD, especially in comparison with providers' interactions with older adults with diabetes.

Conclusion

Diabetes care providers who care for EAWD in adult care settings offer additional insight into the needs of EAWD. These providers observe that many intrapersonal, interpersonal, and structural barriers may impact EAWD self-management, including EAWD roles, priorities, and resource limitations. Providers value communication with their EAWD patients, particularly as it allows providers to make better decisions regarding EAWD care and self-management guidance. Diabetes requires a large degree of patient engagement, and providers acknowledge that engagement for EAWD is often more challenging. However, interventions tailored to EAWD self-management barriers and interventions that address EAWD provider communication needs at visits may offers an opportunity to optimize diabetes management during this life stage as well as health care behaviors and quality of life beyond young adulthood.

HIGHLIGHTS

- Providers describe that Emerging Adults with diabetes (EAWD) may not being as engaged in diabetes self-management activities as older adults
- Providers value EAWD engagement at visits and the EAWD-provider relationship as facilitators of EAWD care
- Providers attribute EAWD engagement, or lack thereof, to multiple factors including lack of perceived risk as a young adult, competing priorities and responsibilities, and structural barriers such as lack of access to appropriate resources and inability to navigate an unfamiliar healthcare system
- Providers view self-management guidance as important to EAWD care but may need additional resources related to organizational and personal capacity for provision of EAWD person-centered self-management guidance such as an ability to offer tailored medical management, to address EAWD psychosocial needs, and to utilize as of yet insufficient best practice communication strategies for EAWD self-management guidance

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Table 1. Interview Questions

What are the major differences between working with young adults with diabetes compared to working with other patients with diabetes?

What do young adults say influences how they are doing managing diabetes?

- What makes it harder to manage diabetes?
- What makes it easier to manage diabetes?

What are your goals for your visits with young adults?

What do you think are your young adult patients' goals for the visit?

What is your typical visit with young adults with diabetes like?

- What information do you share?
- What information do they share/what questions do they ask?

What information is most important for you to share/for them to share at a visit?

When a visit with a young adult goes well, what has happened to make that visit go well?

What has happened when you feel that a visit with a young adult has not gone so well?

Table 2. Demographic Characteristics of Providers (n = 11)

Characteristic	Endocrinologists (n = 4)	Diabetes Nurses (n = 7)
Sex		
Male (n)	2	2
Female (n)	2	5
Years in Practice (Mean, SD)	24.3 (16.6)	14.9 (12.6)
Years at working at hospital (Mean, SD)	17.5 (14.5)	14.8 (15.7)
Years in Diabetes Care (Mean, SD)	n/a	9.4 (10.6)
Estimated average number of Emerging Adults with diabetes seen per week (Mean, SD)	6.8 (3.3)	4.2 (3.1)

Note: SD = standard deviation

Table 3. Topics of Focus, Themes, and Subthemes from Analysis of Provider Interviews

1) Provider Perspective on Quality of Engagement in Diabetes Care Among Emerging Adults

2) Factors Influencing Emerging Adult Engagement in Self-Management
- Intrapersonal Influences
    - Perception of Risk as a Young Adult
    - Emotional Health and Burden
- Interpersonal Influences
    - Busy Lives and Multiple Responsibilities
    - Emerging Adult Social Norms and Activities
- Structural Influences
    - Healthcare Adulting and a New Environment
    - Technology
    - Access to Resources

3) Goals for Diabetes Care Visits
- Provider Perceptions of Emerging Adult Goals
- Progress and Sense of Accomplishment as a Shared Goal

4) Visit Productivity
- Showing Up Matters
- Showing Up is Not Enough
    - Need for Hard Data
    - Need for Active Engagement
- Relationships and Understanding Matter

5) Strategies for Engaging Emerging Adults in Diabetes Management

Table 4. Strategies Providers Described Using to Encourage Emerging Adult Engagement in Diabetes Self-Management

Strategy	Description	Example
Education/Reinforcing Education (n = 7)	Providing core diabetes education and/or reiterating diabetes management basics for self-management	We normally tell them about goals as far as getting your A1C down below seven, exercising throughout the week, making sure your eyes are done once a year, and then taking your medications. (Nurse #3)
Emphasizing Why (n = 7)	Explaining the connections between a patient's self-management behaviors and their health outcomes	I hear so much of, Oh I don't check my sugar, I'm tired of sticking my finger. And I can tell- so many times- I can tell when my sugar is up. It's like, well how can you tell how high it is or how low it is? Well I can't really tell that, but I can tell if it is high. So it's like that. We talk about that and why it's important to actually know the exact number and not just go by feelings and symptoms. (Nurse #6)
Problem Solving Barriers (n = 10)	Identifying specific barriers to self-management and helping patient identify specific actions to overcome these barriers	A lot of times they do have a clue or know what it is but they haven't really themselves made the logical steps to fix it. [One patient] said when he works on the ladder, he just doesn't take his insulin. Well, okay, you don't have to not take it- why don't you just take half as much? So you problem solve those kinds of things. (Endocrinologist #1)
Reframing (n = 8)	Reframing a patient's affective perception of diabetes self-management (making the task seem doable, normalizing diabetes into life goals/activities)	Typically, the way I approach the really hard ones is just do one thing…If I approach them saying if you just do this, just do this one thing, they are like, that's manageable, I can do it. (Endocrinologist #2) What I encourage them to do is to make it unique to you. This is something that you have, and it is different, and it can be complicated, but it doesn't have to be if you go ahead and do what you need to do. So, you're unique so make the disease and the way you handle it unique. You're a football player. You are a basketball player…you are doing what you need to do in order to be able to stay on the team. So, use that as your motivator to take your medicine, eat right, and eat carbs… Diabetes is no longer a disease that is like a monster in the closet that's going to devour you. (Nurse #5)
Navigating Care (n = 5)	Helping a patient navigate the healthcare system through education or linkage to resources	And a lot of times I will tell them when we are doing-even with the insulins-when we are ordering it, I say, if they want make sure when the pharmacy tells you ok your insurance won't pay for this medication, you need to call your insurance to see what they will pay for, and then call me back and then we can send the correct drug to the pharmacy. (Nurse #1)

Paper 3: Event History Calendar Development and Validity Testing for Improved Patient Provider Communication and Diabetes Management for Emerging Adults with Diabetes

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Abstract

Aim: The study purpose was to develop and test content validity, feasibility, and clinical utility of an event history calendar (EHC) as an intervention tool for diabetes communication and management for emerging adults with diabetes (EAWD).

Background: EAWD represent a unique population whose needs require contextualization for better patient-healthcare provider communication and tailored diabetes management. EHC are tools designed to collect contextualized information, enhance cognitive processing, and improve patient-provider communication.

Methods: Analysis of focus groups and interviews with EAWD and diabetes healthcare providers identified topics for inclusion in an EHC for EAWD. Study participants then reviewed EHC and completed questionnaires to assess content validity, feasibility for clinical use, and clinical utility (cognitive processing and communication benefits for diabetes management).

Results: Fourteen topics were identified for EHC inclusion. Topics deemed most relevant by both providers and EAWD included those related to diabetes supplies, medications, physical activity, stress, and diet. EAWD perceived EHC to have cognitive and communication benefits. Providers perceived EHC to provide better contextualization for communication and diabetes management. While EHC were rated easy to complete and feasible for clinical use, providers reported EHC could be refined for feasibility and clinical utility.

Conclusions: EHC may enhance EAWD diabetes management at diabetes visits. Additional design considerations should include refinement of topics based on ability to elicit relevant information for care and use of both structured and unstructured questions to improve completeness and ease of completion while maintaining comprehensiveness to capture diversity of EAWD experiences. Use of digital EHC should be considered.

Key words: Diabetes, emerging adults, event history calendar, communication

Event History Calendar Development and Validity Testing for Improved Patient Provider Communication and Diabetes Management for Emerging Adults with Diabetes

Introduction

For patients with chronic diseases such as diabetes, disease management relies greatly upon a patient's ability to engage in self-care activities outside of the clinic setting. However, care provided at routine diabetes visits provides opportunities to optimize diabetes management and improve health outcomes. As a component of this routine care, provider patient interactions and information exchange influence disease management for both provider and patient, and effective communication at diabetes care visits is associated with better health outcomes.[1,2] Empowering patients and providers to engage in conversation for patient centered self-management has been recognized as a promising means to improve health outcomes.[3]

For emerging adults with diabetes (EAWD), interventions that foster patient provider communication and improve diabetes management and guidance received at diabetes care visits may be especially important. The SEARCH study of youth with diabetes reported poor glycemic control (HbA1c ≥ 9.5%) in 29% of young adults 19 years or older with type 1 diabetes and 47% with type 2 diabetes.[4] Compared to older adults with diabetes, EAWD tend to have poorer self-management, higher diabetes related distress, and high rates of hospitalization for hyperglycemia.[5–8] While the average age of patients with diabetes has decreased slightly with a growing number of patients diagnosed with diabetes at younger ages, diabetes care providers often primarily serve older adults.[8] Yet, emerging adulthood (18-30 years) represents a distinct developmental stage characterized by ongoing transition to adult roles and responsibilities and span an age group with the broadest degree of demographic heterogeneity. The period of emerging adulthood is often characterized or contextualized by ongoing changes in educational, occupational, living situation, and relationship statuses and continued cognitive development.[9] EAWD (and their diabetes care team) must navigate diabetes management in the context of these life events, and recent recommendations call for the development and implementation of diabetes care specifically tailored to the diverse and unique needs of this population of patients.[10,11]

Although interventions for tailoring EAWD care at diabetes visits remain limited, both diabetes care providers (providers) and EAWD report challenges and benefits associated with patient provider visit interactions. Pediatric endocrinologists have reported concern that adult care providers may not be adequately prepared to address developmental challenges of EAWD.[12] EAWD have detailed the importance of an ongoing relationship with non-judgmental diabetes care providers who provide positive support tailored to their needs.[13–16] Compared to providers, EAWD may have different self-management and glycemic goals for diabetes management in the context of competing life priorities.[17–19] Intentionally or unintentionally, patients may not always disclose pertinent information that allows providers to tailor self-management advice, and EAWD in particular report selective disclosure during diabetes care visits.[17,20] Open, effective communication is an important acquired skill for both EAWD learning to problem solve and advocate for themselves as patients and for their providers who must consider the unique circumstances and life stage of EAWD patients in medical decision making and self-management guidance.[21,22]

Event history calendars (EHC) are data collection tools originally designed for enhanced participant recall and collection of sociological data over periods of time.[23] EHC are questionnaires typically organized in a matrix-like format with questions regarding relevant life topics over sequential periods of time (e.g. questions about work, social activities, etc. during the past month, two months ago, and three months ago). The temporal and parallel format of EHC regarding these life topics aid in participant recall and facilitate awareness of links between events, behaviors, and outcomes.[23] The visualization of participant life context within EHC has also been perceived by patients and providers as facilitating fuller communication, patient-centered problem-solving, and tailored care. [24–28] For these reasons, EHC have may be useful tool as an intervention to improve quality of care and communication between EAWD and their diabetes care provider. However, no EHC has been designed specifically for diabetes or EAWD. Given the potential ability of EHC to facilitate patient awareness of self-management behaviors and influences, patient provider communication, and provider ability to provide contextualized, tailored care during patient visits, the aim of this study was to develop an EAWD specific EHC and conduct an initial assessment of the calendar's content validity, feasibility, and utility as a tool for clinical intervention to improve EAWD care during diabetes visits.

Theoretical Framework

Cox's Interaction Model of Client Health Behavior (IMCHB) provided a theoretical framework for EHC development.[29] IMCHB emphasizes the importance of the unique characteristics of each individual client (client singularity). Clients' singularity includes both *background variables* (demographics, social influences, health experiences, and resources) as well as internal *dynamic variables* (intrapersonal characteristics such as affective responses and cognitive appraisal) that influence behaviors and perceptions. For EAWD, in particular, this client uniqueness is especially relevant given the heterogeneity of EAWD as a hallmark of this cohort.[9] Additionally, IMCHB explicitly incorporates patient provider interaction *(*as *client professional interaction)* into the model in recognition of the importance of the role of patient provider interaction and communication in influencing health outcomes.

In this study, IMCHB was adapted to illustrate how EHC could improve patient outcomes as a result of EHC completion at EAWD diabetes care visits (Figure 1). EHC allow patients to present the unique background variables that influence their diabetes management in a manner that improves visualization and contextualization of these variables. EAWD may directly benefit from completion of EHC through cognitive processing that increases awareness of their diabetes self-management and the barriers and facilitators of their diabetes self-management. Additionally, use of EHC to visualize and contextualize pertinent patient specific information may improve patient provider communication that, in turn allows for both better self-management of diabetes and better provider management of diabetes based upon a fuller understanding of a patients' particular needs and challenges.

Research Design and Methods

A mixed methods exploratory sequential design guided EHC development and testing. The study was approved by the Emory University IRB and by the administration of the healthcare system from which participants were recruited. As part of a larger study to explore the perspectives of EAWD and diabetes care providers regarding factors influencing EAWD diabetes self-management and EAWD needs during their diabetes care visits, focus groups and interviews were conducted with EAWD and individual interviews were conducted with providers. Data collected from these discussions were used to help identify topics and questions to include in the EHC and are presented in detail in manuscripts under development (see Paper #1 and Paper #2). Following focus groups and interviews, (the initial qualitative strand of the study), a draft EHC was developed and feedback on the draft EHC was solicited from both EAWD and providers to evaluate potential use of the EHC to improve EAWD care at diabetes visits. These efforts comprised the quantitative strand of the study and are presented in this paper.

EHC Development

EAWD focus groups and interviews and provider interviews were transcribed and analyzed using a mixed concept driven/data driven content analysis approach to identify influences on EAWD self-management and perceptions of EAWD-provider interactions.[30] These findings were used to identify topics for inclusion in the draft EHC based upon: 1) Prevalence of a particular barrier or facilitator to EAWD self-management (e.g. work, busy lives, and diabetes burden were frequently mentioned by both EAWD and providers). 2) The importance of specific information needs or concerns identified by EAWD or providers (e.g. many EAWD reported a desire to address physical problems and primary goal of obtaining diabetes supplies at diabetes care visits). Likewise, many providers identified the need to know more about EAWD diet and routines in order to better ascertain and address problems with blood sugar control. 3) Topics most conducive to maximization of the potential unique benefits of the EHC format. For instance, while specific dietary intake was identified as important to diabetes management, particularly by providers, food diaries are a readily available tool and may allow for more efficient collection of this information, perhaps to be used in conjunction with an EHC.

EHC content was also informed by the seven AADE-7 self-care behaviors of healthy eating, being active, taking medication, monitoring, healthy coping, reducing risks, and problem solving to ensure that topics and questions reflected collection of information related to these key behaviors.[31] Additionally, providers provided further guidance regarding EHC content in general as well as EHC formatting. providers emphasized the need for actionable data with a problem focused orientation as well as a need to simplify the EHC for ease and completeness of calendar completion among EAWD and decreased burden of review for providers. For example, the draft EHC incorporated many quantitative multiple-choice questions and Likert scale items to aid in ease of completion and review of the EHC. Topics and questions were reviewed for actionability to ensure that identified concerns could be realistically addressed during the diabetes visit. Finally, to aid EAWD in ease of EHC completion and memory recall, many EHC questions provided sample answers derived from discussions with EAWD and providers during the qualitative data collection phase. Prior to testing of the finalized draft EHC, the first draft EHC was reviewed and revised by the research team, including an expert in EHC design (KM). A total of fourteen topics were included in the EHC and are presented in Figure 2. Questions included in the EHC were written at a Flesh-Kincaid 5th grade reading level. The EHC also included instructions for EAWD completion written at a 4th grade reading level. (See Supplementary Figures 1 and 2 for EHC instructions and full EHC.)

EHC Content Validity Testing

Sample and Setting

A convenience sample of EAWD and providers who had participated in the qualitative phase of the study also participated in this EHC assessment. EAWD participants were between the age of 18-30 years, had been diagnosed with diabetes for at least a year, and had attended an outpatient adult primary care appointment or diabetes care appointment within the public healthcare system from which participants were recruited. Providers included endocrinologists and diabetes nurses who provided outpatient diabetes care within the healthcare system. All EAWD (n = 14) and providers (n = 10) who had expressed interest in participating in EHC assessment at the time of their focus group or interview participation were invited to participate in the EHC assessment.

Instrumentation

Questionnaires for providers and EAWD were developed to evaluate the draft EHC with respect to content validity, feasibility for clinic use, and clinical utility related to benefits of EHC for diabetes management at diabetes visits. Questionnaire content is outlined in Table 1. For EAWD, content validity assessment also included an additional set of items to assess the clarity of questions asked for each topic. Providers were asked to identify the top four most important topics to include and the four least important to include. Feasibility questions included overall perceived ease of EHC completion or review and time to complete or review the EHC. Providers were also asked about perceived feasibility of implementation in a clinical setting to assess potential challenges to and practicality of implementing the EHC intervention in clinical practice. The adapted IMCHB model was used as a framework to assess EHC utility for diabetes management. EAWD participants were asked questions to assess the ability of the EHC to aid in cognitive processing related to diabetes self-management as well as perceived communication benefits that might lead to better self-management and provider management of their diabetes. Providers were asked about the perceived benefits of the EHC to improve EAWD-provider communication for better diabetes management.

A four-point Likert scale was used to assess content validity items. Feasibility for clinic use (with the exception of time to complete/review EHC) and utility for diabetes management items were assessed on five-point Likert scales. Additional open-ended questions allowed participants to comment regarding content validity, feasibility, and clinical utility for diabetes management. Providers were also asked to identify which healthcare professionals (e.g. doctor, nurse, dietician) should review the calendar if it were to be used in clinical practice.

Data Collection

Attempts were made to contact each interested EAWD by phone to confirm interest in EHC assessment and schedule a phone visit. Eleven EAWD were contacted and interested in participation. Participants were mailed a packet containing a draft EHC, instructions for EHC completion, and an EHC assessment questionnaire prior to the phone visit. During the phone visit, participants were asked to review the instructions for EHC completion and to then complete the EHC. The interviewer recorded the time it took participants to complete the EHC. After EHC completion, the interviewer verbally administered and recorded answers to the questionnaire. Participants returned the completed EHC by mail and were provided $25 gift certificates for their time.

Three completed EHC that were completed by EAWD were selected for provider assessment of the EHC. EHC chosen for provider review were selected based on their representativeness of all returned EHC. Providers were contacted by e-mail to confirm interest in EHC testing. Interested providers were mailed a packet with the three selected EHC that had been de-identified, an EHC assessment questionnaire, and directions for reviewing the EHC and completing the questionnaire. Providers reviewed the ECH and completed the questionnaire at their convenience then returned the EHC and completed questionnaire by mail. While eleven providers participated in the qualitative phase of the study, a total of six participated in EHC review. Those not participating in EHC assessment included one provider who had declined interest in participation during initial interviews and two were no longer eligible due to employment changes.

EHC Data Analysis

Content validity was calculated separately for providers and EAWD using the method described by Polit, Beck, and Own to generate I-CVIs for each calendar topic. [32] A cut-off value of .78 was used to identify items requiring revision or elimination.[32] Means for all Likert items including content validity items were also calculated individually for providers and EAWD. Statistical analyses were performed using SPSS 25 (Chicago, IL).

Results

Description of the Sample

Of the eight EAWD participating in EHC assessment, seven were female and all identified as Black non-Hispanic/Latino or Black Hispanic/Latino. Five of the eight had type 2 diabetes. Of the providers participating in EHC assessment, two were endocrinologists and four were diabetes nurses. Table 2 presents additional characteristics of EAWD and providers participating in EHC assessment.

EHC Content Validity

Providers and EAWD were asked to rate the relevance of each EHC topic. I-CVIs for each topic are presented in Table 3, and mean scores for relevance of each topic are presented in Figure 3. Among EAWD, items addressing the following topics met the I-CVI criteria for inclusion without revision[32]: Diabetes Supplies, Medications, Physical Problems, Physical Activity, Stress, Diet, Blood Sugar Excursions, and Pregnancy. Medications, Blood Sugar Excursions, Diabetes Supplies, and Physical Problems received the highest mean score for relevance by EAWD. Most calendar topics met the criteria for inclusion based upon EAWD ratings of topic clarity; only the topic, Other Questions/Concerns, fell below the .78 I-CVI cut-off. Among providers, Activities/Social Life, Physical Problems, Drug and Alcohol

Use, and Other Questions/Concerns did not meet the I-CVI cutoff. Topics that scored highest for mean relevance among HPC included Pregnancy, Diabetes Questions, Diet, and Medications. Providers were also asked to select the four most and least important topics to include in an EHC, and these selections aligned with mean relevance scores for the most part, with the exception of Pregnancy, which received the highest mean relevance score of all topics by providers but was not identified by any providers as one of the four most important topics for EHC inclusion. When asked to select the four most and least important topics to include in the EHC, providers reported a range of opinions, as indicated by a total of ten topics out of the fourteen being identified as most and least important by at least one provider.

Feasibility for Clinical Use

The time for EHC completion by EAWD ranged from 6 minutes to 32 minutes with a mean completion time of 17 minutes (SD = 7.83). All EAWD found the calendar moderately (n = 3) or very easy (n = 5) to complete, and all agreed that instructions were clear and information asked for was easy to recall (Table 4). The average time for providers to review each EHC was 10 minutes (SD = 8.58) and ranged from 1 minute to 25 minutes. Overall, providers thought that the EHC was easy to review. With the exception of one provider, all providers felt that the EHC would be moderately (n = 2) to very easy to implement in clinic (n = 3), although several provided suggestions regarding how the EHC could be adapted for easier implementation such as converting the EHC into an app or having EAWD complete the EHC prior to the visit and having providers review the EHC prior to the visit. Providers were also asked about which healthcare professionals should review the EHC at a patient visit. The endocrinologist, diabetes nurse, and diabetes nurse educator were identified by 83% of providers, while 67% thought the dietician should review the EHC. Social worker, pharmacist, and mental health specialist were each listed by one provider.

Clinical Utility: Cognitive Benefits/Communication Benefits

The utility of the EHC was assessed with respect to meaning and relevance of the information obtained to support cognitive processing and communication around self-management.[33] Overall, EAWD were interested in sharing the EHC with their providers and reported learning more about their own diabetes self-management and self-management needs when completing the EHC (Table 4). Several EAWD commented that completing the EHC reminded them about the need to take time for self-care activities that they sometimes overlooked (such as exercising, asking for social support, or making time to destress) and the importance of these activities in managing diabetes. Most (n = 5) felt that the EHC would be very helpful in helping them remember issues that they wanted to discuss with their diabetes providers. As one EAWD observed, she would "*look at the calendar and remember this is what I need to talk about*," while another remarked that it would remind her not to "*normalize aches and pains*" and ignore them but to instead discuss these concerns with her diabetes providers. EAWD also perceived the EHC to have potential communication benefits that could result in better diabetes management during diabetes care visits, with mean ratings of communication benefits ranging from 3.75 (helping to talk to the provider at the visit) to 4.38 (receiving tailored diabetes guidance and reminding EAWD of things to ask the provider).

Providers reported that the EHC would improve all assessed aspects of communication with their EAWD, with the EHC rated as "moderately" or "very much" useful for all communication items, excluding one provider rating of EHC ability to help providers engage in conversation with EAWD about their diabetes. Shared decision making and learning information regarding other relevant factors unrelated to EAWD diabetes management challenges in EAWD diabetes care received the highest ratings in terms of utility for communication (Table 5). One provider commented that, "*the calendar…definitely gives a good "picture" of the patients' concerns and overall ability to manage their diabetes. It would also help providers to recommend treatment that fits their lifestyle*," and another observed that the EHC could, "*help prioritize issues that seem to impact the patient more than a provider may realize through [their initial] conversation.*"

Discussion

Content Validity

Overall, the EHC was well received by both EAWD and providers. Review of the EHC by participants indicated that the topics of Diabetes Supplies, Medications, Physical Activity, Stress, and Diet were relevant to both EAWD and providers and given the highest mean relevance scores by both groups of participants. Most providers thought that the selected topics for the EAWD specific EHC were quite comprehensive, but based upon provider comments and EAWD interest in technology, Technology Interest/Usage might be incorporated as a topic as well (e.g. use of social media and internet for information, use or interest in apps or virtual support for diabetes self-management, and interest in medication administration and glucose monitoring technologies). I-CVI scores indicate that several topics may require revision or elimination based upon additional feedback from providers and EAWD. Although blood sugar excursions are highly relevant to diabetes management, several providers observed that objective measures such as these are typically obtained and reviewed with patients as standard practice, so Blood Sugar Excursions could be considered for elimination to decrease patient burden, if needed. Based on the lack of relevance for Other Questions/Concerns and the lack of clarity for this item, this item might be eliminated or revised as a simple free response item allowing EAWD to provide any additional information they would like. For several items, providers also suggested incorporating checkboxes for "not applicable" or "no" to distinguish between incomplete responses versus items that did not apply to that particular patient.

Several items did not meet I-CVI cutoffs but should likely be revised rather than eliminated. While Activities/Social Life and Drugs and Alcohol Use failed to meet the I-CVI cutoff for either providers or EAWD, literature on emerging adulthood and EAWD suggests that these two topics are relevant to

EAWD and that additional input from EAWD and providers is needed to refine these items for relevance. [18,34,35] Additionally, while Physical Problems did not meet the I-CVI cutoff among providers, it did meet the cut-off among EAWD and should likely be retained with revision based on data from the focus groups and interviews with EAWD. These discussions revealed that physical symptoms were concerning to EAWD, and EAWD often wanted providers to address these concerns at visits. A few reported frustrations with physical problems being ignored or dismissed.

Clinical Utility

The data supported clinical utility of the EHC for increased EAWD cognitive processing regarding their diabetes as well as enhanced communication between EAWD and providers at diabetes care visits. Both EAWD EHC ratings and comments revealed that the EHC prompted many EAWD to reflect on diabetes self-management, including their needs and goals. For some EHC, goals provided better insight for providers into how diabetes intersected with other life goals, such as for one participant who desired to lose weight for her upcoming wedding. Providers thought that the EHC helped provide better understanding of the individual EAWD, suggesting that the EHC has the potential to facilitate person-centered care that allows for shared decision making and goal setting as well as more holistic, contextualized individualization of care. Interviews and focus groups with EAWD participants revealed that EAWD may come to a visit with life priorities and goals beyond biometric measures of success assessed by providers, and EHC, when used appropriately, may enhance the perceived value of the diabetes care visit for EAWD when care is aligned with their current needs and values.

There was some variability in the level of detail and completeness of individual EHC. For example, while the EHC provided space for participants to list goals for each topic, several participants listed no goals while others listed goals for almost half the topics. Several EAWD provided a lot of detail for free response items while others did not answer most free response questions. However, even if the level of detail was not elaborate, prompts exist for providers to solicit further information to identify diabetes care needs and concerns (e.g. EAWD reports that social activities impede diabetes management based on a Likert item even though he or she does not describe these problems). Several providers noted this variance and suggested incorporating more multiple choice items rather than open-ended free response questions to encourage EHC completeness. EAWD were given written instruction for EHC completion. However, additional explanation regarding the role of the EHC at their diabetes visit may encourage EAWD to list more goals and respond to all questions (particularly items that ask EAWD to describe problems managing diabetes as related to a particular topic, as this information was identified in provider interviews as helpful to engage EAWD in problem solving and tailoring diabetes guidance).

Feasibility

Most providers thought that the EHC could be feasibly implemented in clinical practice, although providers had suggestions to make the EHC more practical and useful for diabetes care visits. In particular providers thought that while the EHC was comprehensive, they also thought it might be rather lengthy for patients to complete and providers to review. Indeed, compared to other EHC piloted for clinical practice, the current EHC took longer for both EAWD to complete and providers to review.[24,25] As EAWD and providers become more familiar with EHC, time to complete and review may decrease. In addition, further refinement of the EHC may involve eliminating topics as suggested based upon I-CVIs as well as changing some of the open-ended questions to multiple choice and yes/no options to streamline EHC completion and review. One provider suggested limiting the EHC to topics which would be more difficult to ascertain from electronic health records (EHR): "*For example, I get a sense of [blood glucose] control and med adherence/supply difficulties via EHR, but Stress, Questions, and What Else are helpful to guide visits*."

However, based upon the findings of this study, decisions to streamline the EHC should be carefully considered as different topics were important to EHC clinical utility and person-centered care depending on the individual EAWD, and open-ended questions allowed EAWD to elaborate on their unique concerns. Likewise, the range of topics identified by providers as most and least important suggest that different topics may be viewed as more or less important to different providers. EHC design can range from primarily quantitative response items to primarily qualitative questions. Other studies have found that the balance of qualitative to quantitative items in EHC may need to be adapted to a particular population and that a mix of structured and unstructured questions in electronic health records are desired by EAWD.[36,37] For EAWD, the balance of quantitative and qualitative items in an EHC needs further investigation. For instance, multiple choice items may need to incorporate an "other" option with space to elaborate, and EHC directions should encourage use of the "other" option to describe one's unique circumstances for more useful visit interactions with providers.

Despite the time it took to complete the EHC, EAWD participants in the current study did not find the EHC burdensome. Nevertheless, when implementing in clinical practice it may be essential to assess if providers can and do respond to the information that EAWD present in their EHC. EAWD participants indicated the importance of value for time and the need to feel heard by their providers. If these conditions are not meet, EAWD may be reluctant to invest time in completing EHC. Providing information and training to providers in the use of EHC may facilitate EHC utility. Some providers also suggested having EAWD complete the EHC prior to the visit and allowing providers time to review the EHC before seeing the patient.

Limitations and Future Steps

This study represented a first step towards developing an EAWD specific EHC appropriate for clinical implementation and facilitation of EAWD care at visits. Although EAWD were encouraged to provide open, honest feedback for what was described to participants as a draft EHC in progress, questionnaires were self-report and administered directly to EAWD by the research investigator, which may have lead to reporting biases. A complicating factor in interpreting I-CVI scores among EAWD, who by definition are a highly heterogenous age group,[9] was the rating of some topics based on individual relevance rather than collective relevance; for instance, EAWD who did not work tended to rate Work/School lower, and EAWD who perceived that they had less social support tended to rate Support lower. Even among this small sample of EAWD, it was evident that the relevance and utility of topics varied by individual and individual circumstance.

In recognition of the importance of including multiple stakeholders in intervention development, both diabetes care providers and EAWD were invited to participate in the study. However, a small sample of EAWD and providers participated in this study and may not be representative of the larger population of EAWD and diabetes providers caring for EAWD. Likewise, the EAWD participating in EHC assessment had also participated in focus groups and interviews. Education and literacy level has been associated with EHC benefit in prior research, with less educated participants reporting greater benefit.[38,39] While the sample size was not large enough to assess differences by education level, in this study, participants not completing high school tended to give lower ratings for some EHC assessment items. Further testing of the EHC should include a broader range of EAWD and providers, especially as EAWD represent a diverse group. Broader testing may identify additional topics or need for EHC revisions as well as differences among subsets of EAWD in regards to EHC clinical utility.

EHC development can be strengthened by an iterative process. Initial EHC review was primarily limited to quantitative feedback. Additional focus groups with EAWD and providers to review the EHC would allow for more robust discussion and feedback for EHC refinement. For example, follow up may provide better insight into why topics seemingly pertinent to emerging adults, such as Drug and Alcohol Use and Activities/Social Life, did not meet I-CVI cutoffs. Discussions would also be helpful in generating a broader range of multiple-choice options allowing EAWD to describe problems related to diabetes management in a more succinct manner than currently solicited in free response items. Moreover, testing the EHC in actual clinic visits would lead to more accurate assessment of feasibility, cognitive benefits, and, especially, EAWD-provider communication benefits. Testing in a clinic setting could incorporate additional measures to assess provider capacity to act upon information presented in EHC, whether by providing affective support or tailored information to EAWD, adapting medical decision making, or directing EAWD to appropriate resources.

Lastly, the EAWD specific EHC should be considered for implementation as a digital app. Implementation as a digital app may enhance feasibility for clinical use by allowing EAWD to complete the EHC prior to the visit and allowing providers to easily review the record prior to seeing the patient. Digital presentation may better address challenges associated with the paper EHC such as difficulty providing space for EAWD responses, provider difficulty reading responses, and missing information. Use of electronic EHC have already been piloted in other settings,[40,41] and the vast majority of EAWD already engage with social media platforms including for the sharing of health information,[42] suggesting that an EAWD specific eEHC merits further investigation.

Conclusion

EHC are tools for intervention that allow for collection of information in a manner that facilitates cognitive processing and visualization of life context. In this study an EHC was developed and tested to determine content validity, feasibility, and utility for clinical care of EAWD. Overall, the EHC seems to have high content validity, although the EHC may benefit from further testing and revision. Assessment of this EAWD specific EHC suggests the EHC has the potential to improve diabetes communication and diabetes management for EAWD at diabetes care visits. Even with varying levels of detail provided by EAWD in completing their EHC, both EAWD and providers thought that EHC implementation was feasible and had utility in regard to cognitive processing and patient-provider communication for diabetes management. With further refinement for implementation and clinical utility, the value of the EHC can be optimized to enhance the value of diabetes care visits for EAWD and providers in tailoring diabetes care to this unique and diverse young adult population.

HIGHLIGHTS

- An Event History Calendar (EHC) designed for Emerging Adults with diabetes (EAWD) may be an effective tool for improving diabetes care for EAWD during diabetes visits
- EAWD perceive EHC to enhance reflection of their own diabetes care needs and self-management behaviors
- EAWD and healthcare providers perceive that EHC may lead to more tailored care and better patient-provider communication
- EHC should be considered for further refinement and implementation in digital form to improve ease of completion and review while still presenting fuller patient life context to support EAWD diabetes management

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Figure 1. Theoretical Model Adapted from Cox's Interaction Model of Client Health Behavior

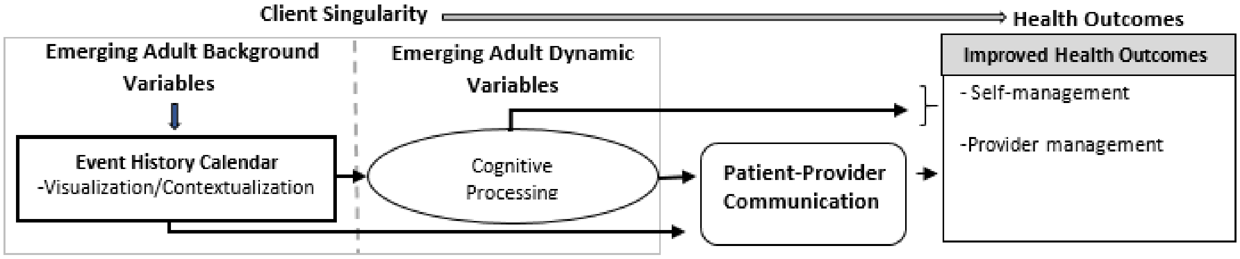


Figure 2. Topics Included in Draft Event History Calendar

Event History Calendar Topics+

- Work/School
- Diabetes Supplies
- Activities/Social Life
- Medications
- Physical Problems
- Physical Activity
- Stress
- Support
- Diet
- Blood Sugar Excursions
- Diabetes Questions
- Drug and Alcohol Use
- Pregnancy
- Other Concerns/Challenges

+ Event history calendar also included a “Goals” section for Emerging Adults to describe goals related to each topic

Table 1. Areas of Validity, Feasibility and Clinical Utility Assessment of Event History Calendar

Assessment	**Emerging Adult Questionnaire**	**Provider Questionnaire**
Content Validity	Topic Relevance Topic Clarity	Topic Relevance
Feasibility for Clinic Use	Ease of Completion Time to Complete	Ease of Review Time to Complete Feasibility of Implementation
Clinical Utility for Diabetes Management	Cognitive Processing Communication	Communication

Table 2. Characteristics of Emerging Adults and Providers Participating in Event History Calendar Assessment

Characteristic	n (%) or Mean (SD)
Emerging Adults (n = 8)	
Sex	
Female	7 (87.5%)
Male	1 (12.5%)
Age	26.6 (3.7)
Race/Ethnicity	
Black, Non-Hispanic/Latino	7 (87.5%)
Black, Hispanic/Latino	1 (12.5%)
Diabetes Type	
Type 1	3 (37.5%)
Type 2	5 (62.5%)
Education	
Some High School	2 (25.0%)
High School/GED	0 (0.0%)
Some College	3 (37.5%)
Associate or Bachelor's	3 (37.5%)
Health Insurance	
Yes	3 (37.5%)
No	5 (62.5%)
Last HbA1c+	9.2 (1.90)
Providers (n = 6)	
Sex	
Female	5 (83%)
Male	1 (17%)
Years in Practice++	14 (12.9)
Provider Type	
Endocrinologist	2 (33%)
Diabetes Nurse	4 (66%)

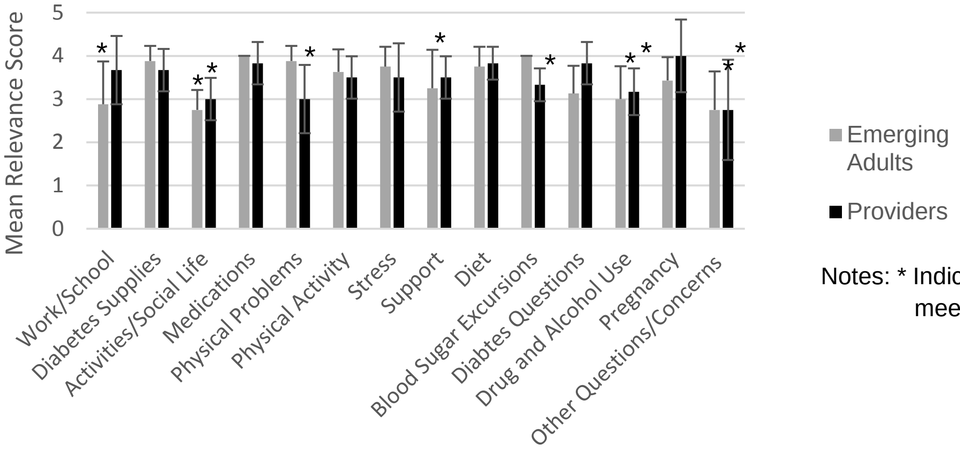
Notes: + Not all Emerging Adults knew their HbAl1c, n = 5
++ Years in diabetes care for nurses
SD = standard deviation

Table 3. Content Validity Indices

Topic	**Relevance I-CVI Providers** n = 6	**Relevance I-CVI Emerging Adults** n = 8	**Clarity I-CVI Emerging Adults** n = 7
Work/School	1.00	.50+	.88
Diabetes Supplies	1.00	1.00	1.00
Activities/Social Life	.67+	.75+	1.00
Medications	1.00	1.00	1.00
Physical Problems	.50+	1.00	.86
Physical Activity	1.00	1.00	1.00
Stress	.83	1.00	.86
Support	.83	.75+	1.00
Diet	1.00	1.00	1.00
Blood Sugar Excursions	.67+	1.00	1.00
Diabetes Questions	1.00	.88	1.00
Drug and Alcohol Use	.67+	.75+	1.00
Pregnancy ^	1.00	1.00	.80
Other Questions/Concerns	.50+ §	.50+	.71+

Notes: SD = Standard deviation
+Candidate for revision (I-CVI < .78)
^ n = 7 for patient relevance, n = 6 for patient clarity
§ n = 4 due to missing data from two providers

Figure 3. Mean Relevance Scores for Event History Calendar Topics- Emerging Adults vs. Providers



Notes: * Indicates topic did not meet I-CVI cut-off

Table 4**.** Event History Calendar Assessment Ratings by Emerging Adults

Item	**Mean (SD, min-max)**
Feasibility for Clinic Use	
Ease of calendar completion	4.63 (.52, 4-5)
Instructions clarity	5.00 (.00, n/a)
Information recall	5.00 (.00, n/a)
Cognitive Benefits	
Learn about self-management influences	3.38 (1.30, 1-5)
Learn about diabetes needs	3.25 (1.75, 1-5)
Learn about ways to better manage diabetes	3.38 (1.60, 1-5)
Communication Benefits	
Interest in sharing with provider	4.13 (1.26, 2-5)
Help talk with provider	3.75 (1.16, 2-5)
Remind of things to ask provider	4.38 (.92, 3-5)
Better provider management of diabetes	4.25 (.89, 3-5)
More tailored diabetes guidance	4.38 (.92, 3-5)

Notes: SD = Standard deviation
Higher scores indicate more favorable response

Table 5. Event History Calendar Assessment Ratings by Providers

Item	Mean (SD, min-max)
Feasibility for Clinic Use	
Ease of calendar review	4.83 (.41, 4-5)
Feasibility of implementation	4.17 (1.17, 2-5)
Communication benefits	
Information about patient self-management challenges	4.50 (.84, 3-5)
Other relevant information about patients	4.83 (.42, 4-5)
Engage in conversation	4.50 (.84, 3-5)
Provider decision making	4.67 (.52, 4-5)
Shared decision making	4.83 (.41, 4-5)
Tailored diabetes management guidance	4.67 (.52, 4-5)

Notes: SD = Standard deviation

Higher scores indicate more favorable response

Supplementary Figure 1. Event History Calendar Instructions

"My Life, My Diabetes" Calendar Instructions

The *"My Life, My Diabetes Calendar"* asks you about your activities and things that may have influenced how you are doing with diabetes over the past few months. The information you provide will help your nurses/doctors know you better and better address your health needs.

Directions for completing the form:

Step #1. Starting with the first topic, "My Work/School," use the space provided under each period of time to answer the questions asked about work/school over each period of time:

- ✓ This past week (the past 7 days)
- ✓ This past month (the past 30 days, not including the past week)
- ✓ Two and three months ago

Step #2. Use the last column "My Goals" to write down any goals you have related to diabetes for that topic.

Step #3. Continue with the rest of the topics on the form, answering the questions for each period of time and writing down any goals you have. (See example below)

Topic

Periods of Time

My Goals

Topic	**This Past Week** (0-7 days ago)	**This Past Month**	**Two & Three Months Ago**	**My Goals**
My Work/School				*Be able to check sugars while at work*
Were you in school?	Yes [✓ No]	Yes [✓ No]	Yes [✓ No]	
Were you working?	[✓ Yes] No	[✓ Yes] No	Yes [✓ No]	
What was your job/jobs?	Jobs: *Construction*	Jobs: *Construction*	Jobs: *Unemployed*	
What problems did you have trying to manage diabetes while working/going to school?	*Too busy to check sugars*	*Low sugars at work, too tired to deal with diabetes after work*		
Was diabetes a problem in trying to get or keep a job? Describe	Yes [✓ No]	[✓ Yes] No *Had to take off work because sick*	Yes [✓ No]	

Supplementary Figure 2. Event History Calendar for Emerging Adults with Diabetes

"My Life, My Diabetes" Calendar

Topic	This Past Week (0-7 days ago)	This Past Month (not including this week)	Two & Three Months Ago	My Goals
My Work/School				
Were you in school?	Yes No	Yes No	Yes No	
Were you working?	Yes No	Yes No	Yes No	
What was your job/jobs?	Jobs:	Jobs:	Jobs:	
What problems did you have trying to manage diabetes while working/in school?				
Was diabetes a problem in trying to get or keep a job? How so?	Yes No	Yes No	Yes No	
My Diabetes Supplies				
Did you have any trouble getting diabetes supplies? (Circle if Yes)	Meds Strips Syringes Other	Meds Strips Syringes Other	Meds Strips Syringes Other	
Did you run out of any diabetes supplies? (Circle if Yes)	Meds Strips Syringes Other	Meds Strips Syringes Other	Meds Strips Syringes Other	
Did you have any problems with your meter or glucose monitor?	Yes No Don't have one	Yes No Don't have one	Yes No Don't have one	
My Activities/Social Life				
Did you usually have a regular weekly schedule?	Always Often Rarely Never	Always Often Rarely Never	Always Often Rarely Never	
What main activities/big events did you have going on? (Examples: Going out with friends, taking care of kids, church, doctor visits, wedding, vacation)				
On a scale of 1-5, with 1 being "Not at All" and 5 being "A Huge Amount," how much did your daily activities keep you from doing what you need to do to manage diabetes (i.e. eat healthy, check sugars, take medications)?	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	
What problems did you have trying to manage diabetes while doing these activities? (Examples: didn't want to take insulin/check sugars in front of others, inconvenient, no healthy food available, no diabetes supplies, forgot, worry about lows)				

Topic	This Past Week (0-7 days ago)	This Past Month (not including this past week)	Two & Three Months Ago	My Goals
Taking My Medications Were there times you did not take your diabetes medication? Reason(s) you did not take medication? (Examples: out of supplies, money, busy, forgot, tired of taking medication) When you took your medications, what medication side effects did you have? (Examples: low sugars, upset stomach) What changes to your medication/insulin (i.e. amount, timing) did you make for yourself? What was the reason?	Yes No	Yes No	Yes No	
Aches and Pains What physical problems did you have that you were worried about? (Examples: foot pain, pain from shots, blurry vision)				
Keeping Active What exercise did you do? Describe the type and amount (times a week, duration) What made it hard to exercise? (Examples: No time, too tired, no place to exercise, worried about sugars)				
My Life Stress On a scale of 1-5, with 1 being "None" and 5 being "A Huge Amount" A) How much stress did you have? B) How much stress was related to diabetes?	1 2 3 4 5 1 2 3 4 5	1 2 3 4 5 1 2 3 4 5	1 2 3 4 5 1 2 3 4 5	
My Support Who helped you with diabetes (i.e. get supplies; provide transportation, information, encouragement)? (Examples: Mom, friend, pharmacist, boyfriend)				

Topic	This Past Week (0-7 days ago)	This Past Month (not including this past week)	Two & Three Months Ago	My Goals
My Diet Did you usually eat at about the same times each day?	Yes No	Yes No	Yes No	
IF YES: At what times did you typically eat meals?	Meal Times	Meal Times	Meal Times	
○ Circle your biggest meal. ✓ Check your smallest meal.				
IF NO: As best you can, list the time of your biggest and smallest meals.				
What places did you (or whoever prepares your meals) usually buy your food from? (i.e. List names of restaurants, grocery stores, convenience stores and restaurants)				
Who prepares your meals most days? (Circle all that apply most days)	I do Someone else at home Buy meal outside house	I do Someone else at home Buy meal outside house	I do Someone else at home Buy meal outside house	
What problems did you have eating healthy? (Examples: Not sure what was healthy, lack of good options, cost, no time to eat, too many temptations)				
My Blood Sugars Did you have problems with high or low sugars? (Circle if Yes)	Highs Lows	Highs Lows	Highs Lows	
What do you think caused these highs or lows?				
Questions I Had about Diabetes Did you ask or search for information about diabetes concerns?	Yes No	Yes No	Yes No	
What diabetes related questions did you have during this time?				
Whom did you ask or where did you find answers?				

Topic	This Past Week (0-7 days ago)	This Past Month (not including this past week)	Two & Three Months Ago	My Goals
Habits Did you smoke/use tobacco, drink alcohol, use drugs? Circle any that you did.	Smoke Alcohol Drugs	Smoke Alcohol Drugs	Smoke Alcohol Drugs	
WOMEN ONLY: Pregnancy Were you trying to get pregnant?	Yes No	Yes No	Yes No	
Were you trying to prevent pregnancy (i.e. birth control, condoms, abstinence)?	Yes No	Yes No	Yes No	
What Else? What other questions, concerns, or information do you want to share with your doctor/nurse about this period of time?				
What or who else made it harder to manage diabetes?				
What or who else made it easier to manage diabetes?				

Integrative Summary

Overview

Diabetes is a chronic disease that requires ongoing management by both patients and providers. As of 2018, over 13% of the population of the United States had been diagnosed with diabetes, and these numbers are expected to increase, including among emerging adults (18-30 year olds).[76,77] Emerging adulthood represents a unique phase of transition from childhood to full adulthood during which emerging adults with diabetes (EAWD) are not only taking on new roles and responsibilities as adults but are coping with the many tasks associated with diabetes self-management. EAWD often struggle with increased psychosocial burden and poor glycemic control, yet research specific to identifying and addressing the needs of this population remains limited.[3–6] The purpose of this study was to investigate the perceptions of EAWD and diabetes healthcare providers (providers) regarding the influences on EAWD diabetes self-management as well as their perceptions of EAWD-provider interactions during healthcare visits and to investigate the use of a potential intervention, an event history calendar (EHC), to facilitate EAWD care at diabetes visits. Specifically, the study had three aims:

Aim 1: To explore the perspectives of EAWD and providers regarding EAWD diabetes self-management and patient-provider communication about diabetes management during diabetes care visits among minority and socioeconomically diverse EAWD

Aim 2: To develop an EAWD specific EHC based on topics identified by EAWD and providers as relevant to addressing EAWD diabetes care and management at diabetes care visits

Aim 3: To assess content validity of the EHC, feasibility, and clinical utility of using an EHC approach to improve EAWD-provider communication and cognition of patient life context during diabetes care visits

Findings

Study data were analyzed and the findings presented as three separate papers. Paper #1 presents findings regarding the perceptions of EAWD regarding influences on diabetes self-management as well as their perceptions of their interactions with providers during diabetes care visits. Paper #2 presents the findings from a parallel investigation of the perceptions of providers (endocrinologists and diabetes care nurses) regarding influences on EAWD diabetes self-management and provider perceptions of their interactions with EAWD during diabetes care visits. Paper #3 describes the development of an EAWD specific EHC and the initial testing of this EHC as a potential intervention to improve EAWD care during diabetes care visits.

Examined as a whole, perceptions of EAWD and providers presented in Paper #1 and #2 illustrated ways in which EAWD and providers views converged and diverged to provide a fuller understanding of perspectives, challenges, and needs regarding diabetes care for EAWD. EAWD and providers both identified a combination of intrapersonal, interpersonal, and structural influences on diabetes self-management among EAWD including the psychological burden of diabetes, particularly in the context of a life stage during which EAWD are balancing many roles and responsibilities. While many EAWD acknowledged that coming to terms with having diabetes as a young adult was difficult, providers expressed more strongly a concern that EAWD did not perceive or act in in manner that addressed the real risk of diabetes complications associated with lack of daily diabetes management and glycemic control. However, EAWD did express fear of complications, especially hypoglycemia and current physical problems.

When discussing social interactions and diabetes self-management, many EAWD observed that positive motivation and support provided by family was helpful in diabetes self-management. Providers focused more on the way that social norms and young adult social activities challenged diabetes self-management. While EAWD participants identified several structural challenges associated with self-management, these challenges were much more commonly discussed by providers, and providers articulated a complex interplay of factors impeding EAWD self-management. The healthcare system itself was perceived by EAWD as influencing diabetes self-management and care; for EAWD the healthcare system represented a safety-net for access to resources at the same time that EAWD were frustrated with the quality of care provided within a safety-net system. Providers observed challenges with EAWD navigation of the healthcare system and expressed frustration that the healthcare system did not always afford their EAWD access to some of the technologies and therapeutics most appropriate to for their EAWD patients.

EAWD and providers both acknowledged the importance of the ongoing patient provider relationship in supporting diabetes care. EAWD illuminated the role of positive support and understanding as well as care that is tailored to their specific needs as young adults and as individuals. Ongoing relationships within the diabetes care program were valued by both EAWD and providers. Both EAWD and providers appeared to acknowledge the potential for diabetes care visits to offer more than the visit might currently offer. For EAWD who often felt that visits were fairly standardized, tailored information and encouragement in their self-management efforts were desired. In contrast, for providers, a common theme regarding their interactions with EAWD was a desire for greater EAWD engagement, and more complete information for decision making was viewed as a desired but often unmet goal. These views were not necessarily divergent, as tailored care that met personal needs and situation was a common theme among both groups of participants. Overall, providers and EAWD shared several common overarching goals for diabetes care visits, including a desire for useful information exchange and progress. However, clarity and mutual understanding of the path and criteria for achieving these broader shared goals may have been less evident.

Findings from the focus groups and interviews with EAWD and providers generated topics for inclusion in the EAWD specific EHC. A total of 14 topics were selected for inclusion: Work/School, Diabetes Supplies, Activities/Social Life, Medications, Physical Problems, Physical Activity, Stress, Support, Diet, Blood Sugar Excursions, Diabetes Questions, Drug and Alcohol Use, Pregnancy, Other Concerns/Challenges. Additionally, based upon focus groups and interviews, the EHC was designed to solicit EAWD goals and problems with the intention of providing a platform for shared goal setting and problem solving. Seven topics were identified for potential revision or exclusion based upon I-CVI scores: Work/School, Activities/Social Life, Aches/Pains, Support, Blood Sugar Excursions, Drug and Alcohol Use, and Other Concerns/Challenges while both EAWD and providers rated Diabetes Supplies, Medications, Physical Activity, Stress, and Diet as highly relevant to diabetes care. However, discrepancies emerged between the relevance of topics based on EHC assessment relevance scores as compared to topics identified as relevant based upon focus groups and interviews and based upon other research literature on EAWD. This suggests the need for additional EHC review and consultation with EAWD and providers before implementation. For example, work was a common challenge to diabetes self-management for EAWD, but Work/School failed to meet the I-CVI cutoff in EHC assessment. Likewise, topics such as Activities/Social Life and Habits were discussed by providers during interviews and have been observed as influencing EAWD diabetes self-management, yet Activities/Social life also failed to meet the I-CVI cutoff criterion.

Nevertheless, EAWD thought that the EHC facilitated cognitive processing regarding diabetes self-management. EAWD and providers both indicated that the EHC could be an effective tool for improving communication and care at diabetes visits. Overall findings from the EHC assessment suggest that the EAWD specific EHC designed based on interviews and focus groups with EAWD and providers has the potential to support effective diabetes management at and between diabetes care visits.

Strengths/Limitations

Emerging adults are often not studied as a distinct population despite their unique needs. This study sought to identify the self-management challenges of EAWD as a distinct population. Moreover, this study included subsets of EAWD who are often underrepresented in studies of EAWD: a large number of minority and socioeconomically diverse EAWD, EAWD not attending or having attended college, and EAWD with type 2 diabetes. EAWD data collection occurred through both focus groups and interviews, a complementary data collection strategy, which may lead to more robust data collection.[78]

Additionally, few interventions have been developed specifically for EAWD. This study sought to develop and test an intervention tailored for EAWD diabetes care. The EHC developed as part of this study provides a mechanism to facilitate EAWD-provider communication and reflection regarding contextualized individual experiences relevant to diabetes management and holistic care. Development of effective interventions must be grounded in the realities of clinical practice and a holistic understanding of the problem that an intervention is intended to address. While providers bring professional knowledge to their diabetes care practices, EAWD bring their own expertise and experience to diabetes care visits. In recognition of these factors, this study solicited the views of both EAWD and provider in an attempt to gain a broader perspective provided from multiple stakeholders in EAWD diabetes management and care and to develop an intervention with feasibility and efficacy within the parameters of clinical practice.

However, sample size and diversity were limited by the challenges of participant recruitment and retention. Despite multiple EAWD recruitment strategies, all EAWD were recruited from telephone contacts as a follow up after letter mailings, and of those EAWD receiving letters only 12% participated in the study. This group may not be representative of the larger population of EAWD within the public healthcare system. Moreover, the majority of EAWD participants had type 2 diabetes, most were female, with fewer younger emerging adults participating as compared to older EAWD. While most of the EAWD in this study had type 2 diabetes, during interviews providers often associated EAWD with type 1 diabetes and older adults with type 2 diabetes. Provider views may have been influenced by this schema of thinking. This discrepancy may have accounted for some of the differences between the views of EAWD and provider study participants. Likewise, this study was limited to participants within one healthcare system and may not represent the views of EAWD and providers within the distinct diabetes care practices and organizational structure of other public or private healthcare systems.

Findings from the study may have been limited by data collection strategies as well. Rich description in qualitative research includes extended time with participants to gain rapport and enhance quality and completeness of data.[74] In this study, time constraints related to the number and duration of interactions with participants may have limited the richness of data collection, especially during focus groups in which multiple participants were asked to share their perspective within a limited timeframe. Social dynamics of focus groups, social biases, and interviewer/moderator experience may have influenced information exchange and, therefore, the quality of the study findings. Although EHC testing solicited both quantitative and qualitative feedback, the testing was limited in scope and additional follow up would allow for further exploration of the content validity, feasibility, and clinical utility of the EHC.

Implications for Research

Several study findings provide insight to guide future research regarding EAWD diabetes management. While this study provided additional perspective from both EAWD and providers on diabetes self-management and diabetes care interactions among socioeconomically diverse EAAWD, additional depth of insight may be needed to better assess for differences in perspectives and needs of certain subsets of EAWD based on characteristics such as gender, diabetes type, and timing of diagnoses (diagnosis in pediatric versus adult care setting). Information from provider interviews indicated that additional support and resources may be helpful to providers when caring for EAWD, but interviews did not specifically focus on provider needs. Therefore, additional follow up with providers should explore provider needs in working with EAWD, including need for additional training regarding the developmental characteristics of EAWD as well as provider need for organizational support, technology, and services tailored to EAWD care. Likewise, the EAWD specific EHC developed as a result of this study will require additional refinement. An iterative process of refinement, review, and testing, especially within a clinical setting, will enhance the feasibility and clinical utility of the EHC.

Findings from this study also suggest that additional research is required to identify ways to better engage EAWD in diabetes self-management at and between visits with providers. Based upon the challenges identified, efforts to better understand and facilitate engagement may require input from EAWD, providers, as well as healthcare administration given a complex interaction of intrapersonal, interpersonal, and structural barriers to engagement in diabetes management among EAWD. Barriers to engagement may extend to EAWD recruitment into research studies, perhaps in part due to the nature of emerging adulthood as well as EAWD lack of connection with the healthcare system. Yet, once recruited, most EAWD in this study were interested in sharing their perspective, and all who were contacted for EHC assessment were interested in participation. Successful retention indicates that EAWD may be willing to contribute to research activities intended to improve EAWD care and outcomes once initial recruitment barriers are overcome and rapport is established.

Observational studies of EAWD and provider interactions as well as post visit interaction interviews may yield additional detail and more objective evaluation of EAWD-provider interactions. Strategies used by providers could be assessed in relation to EAWD perceptions of those strategies to determine what strategies are well received by EAWD and effective in improving EAWD health outcomes. For instance, EAWD discussions suggested that EAWD may be receptive to affective reframing and that EAWD need to hear information they perceive as new and relevant as opposed to hearing the same general advice for self-management. Likewise, while providers described attempting to promote glycemic control by emphasizing potential complications, EAWD feared complications but did not always seem receptive to the “threat” of complications. Therefore, EAWD-provider interactions warrant observational follow up to further understanding of the dynamics and effectiveness of these interactions. Additionally, observational investigations could incorporate a comparative approach, comparing EAWD-provider interactions to older adult-provider interactions, to ascertain and evaluate differences in these interactions and their outcomes.

Implications for Practice

The perspectives of EAWD and providers provided guidance regarding factors to be addressed in caring for EAWD. Holistic self-management barriers should include assessment and intervention related to the emotional, social, and structural factors contributing to diabetes self-management. At an interpersonal level, communication should emphasis person-centered care that focuses on relationship building, positivity, individualization of guidance and medical decision making, and shared decision making and goal setting.[79] EAWD perspectives in this study reaffirmed the high psychosocial burden among EAWD and the need for assessment and intervention to address psychosocial distress. Additionally, diabetes management programs for EAWD should consider implementation of peer group support as well as assistance navigating the healthcare system.

For EAWD who must balance diabetes with other life priorities such as work and school, the perceived value of the visit must outweigh the opportunity costs of overcoming barriers to these visits. Thus, tailoring of care to provide practical advice that can be used within the context of an individual EAWD’s daily life is vital to encouraging attendance and engagement at and between visits. Goal setting through shared decision making should be considered as a means to enhance the value of diabetes visits. Additionally, mutual understanding among an EAWD and their providers of the role of engagement and sharing of information in the provision of appropriate, individualized care has the potential to enhance the perceived value of diabetes care visits for EAWD and for providers. Continuity of care (ongoing connection to individual providers and the healthcare system as a whole) was identified as enhancing the value of patient provider interaction. Incorporating “just in time” advice and flexible visit scheduling in clinical practice should be considered as a means to enhance continuity of care. A focus on establishing continuity of care with individual providers may also contribute to relationship building. In this study, even periodic phone calls from providers between visits were appreciated by EAWD and providers as an effective way to support EAWD diabetes management and enhance the value of care.

Initial evaluation of the EAWD specific EHC indicates this tool could be implemented in clinical practice to improve EAWD-provider communication and person-centered care. Additionally, results of this study suggest EHC could be used to promote EAWD reflection on their own diabetes care needs as well as actions they could take to improve their self-management. However, the burden of EHC completion must be minimized to enhance use and benefit of EHC in practice. Effective implementation of EHC in practice will also benefit from EAWD and provider understanding of the role of EHC in communication, problem solving, individualizing care, and goal setting; for providers, this may require formal training and familiarization in the use of EHC. To facilitate practical implementation of EHC in the clinic and to take advantage of EAWD familiarity with technology, EHC could be implemented in digital format.

Conclusion

EAWD and providers described multiple influences on self-management. EAWD often need specific advice and encouragement while providers need information to provide tailored diabetes care and management. Engagement barriers related to the intrapersonal burden of diabetes, interpersonal aspects of balancing life priorities as well as structural barriers related to access to resources may impede diabetes management among EAWD. Additional research is needed to provide diabetes care targeted to the life context of EAWD and to ensure EAWD ability to engage in diabetes care management and with diabetes care systems for lifelong healthy living. However, EAWD-provider visits that emphasize holistic, person-centered care and contextualization of individual EAWD lives, as potentially facilitated by an EAWD specific EHC, could contribute to enhanced diabetes self-management, provider decision making, and, ultimately, improved outcomes for this unique EAWD population.

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Appendices

Appendix 1: Emerging Adult Demographic Questionnaire

Please answer the following questions to help us learn about you and your diabetes care. If a question does not make sense, please feel free to ask the research team for help.

Demographics

1. What is your age? ______

2. What is your gender?

☐ Male

☐ Female

☐ Other

3. What is your race? (Check all that apply)

☐ American Indian/Alaska Native

☐ Asian/Pacific Islander

☐ Black

☐ White

☐ Other: _________

4. What is your ethnicity?

☐ Hispanic

☐ Non-Hispanic

5. Do you currently have health insurance?

☐ Yes

☐ No

Diabetes Information

6. What type of diabetes do you have?

☐ Type 1

☐ Type 2

7. In what year did you get diabetes? ________

8. What was your last Alc? ____________ ☐ Do not know

9a. Check all the diabetes medicines you currently take:

☐ Insulin

☐ Pills

☐ Non-insulin shots (examples: Byetta, Bydureon, Victoza, Trulicity)

9b. Check all of the following equipment that you use:

☐ Insulin pump

☐ Continuous glucose monitor

10. In the past year, how many times have you:

a. Seen a doctor for routine diabetes visits? ______

b. Gone to the ER or urgent care for high or low blood sugars? _____

c. Spent the night in the hospital for high or low blood sugars?_____

11. What best describes how you feel about how well you are managing your diabetes?

☐ Very happy with how things are going

☐ Somewhat happy with how things are going

☐ Somewhat unhappy with how things are going

☐ Very unhappy with how things are going

Work/Life Situation

12. Are you currently working?

☐ Yes, full-time

☐ Yes, part-time

☐ No

13. Do you currently go to school?

☐ Yes, full-time

☐ Yes, part-time

☐ No

14. What is the highest amount of education you have had?

☐ 8th grade or less

☐ Some high school

☐High school/GED

☐ Some college

☐ Associate or bachelor's degree

☐ Graduate degree

15. Are you married?

☐ Yes

☐ No

16. Do you have children?

☐ No

☐ Yes

17. Which best describes who you live with: (Check all that apply)

☐ I live with my children

☐ I live with my partner/spouse

☐ I live with relatives other than children or spouse

☐ I live with roommate(s) who are not family

☐ I live alone

☐ Other. Describe: ______________________________________

Appendix 2: Emerging Adult Event History Calendar Questionnaire

The purpose of this calendar is to improve the information and care that you receive at your diabetes appointments by providing you and your healthcare providers a better picture of things going on in your life that might affect how well you are able to manage diabetes.

Content Validity: Topic Relevance

If you were to share your calendar with your diabetes doctor/nurse at your appointment, how important do you think it would it be to include each of the topics in the calendar? On a scale of 1 to 4, with 1 being "Not at all important" and 4 being "Very important" please tell me the number that best indicates your answer.

Calendar Topic	Not at all important ☆☆☆	Somewhat important ★☆☆	Quite important ★★☆	Extremely important ★★★
My Work/School	1	2	3	4
My Diabetes Supplies	1	2	3	4
My Activities/Social Life	1	2	3	4
Taking My Medications	1	2	3	4
Aches and Pains	1	2	3	4
Keeping Active	1	2	3	4
My Life Stress	1	2	3	4
My Support	1	2	3	4
My Diet	1	2	3	4
My Blood Sugars	1	2	3	4
Questions I Had about Diabetes	1	2	3	4
Habits	1	2	3	4
Pregnancy (Women only)	1	2	3	4
What Else	1	2	3	4

Content Validity: Topic Clarity

On a scale of 1 to 4, with 1 being “Not at all clear” and 4 being “Very clear” please circle the number that best indicates the clarity of each calendar topic (how easy it was to understand what was being asked).

Calendar Topic	Not at all Clear ☆☆☆	Somewhat clear ★☆☆	Mostly clear ★★☆	Very clear ★★★
My Work/School	1	2	3	4
My Diabetes Supplies	1	2	3	4
My Activities/Social Life	1	2	3	4
Taking My Medications	1	2	3	4
Aches and Pains	1	2	3	4
Keeping Active	1	2	3	4
My Life Stress	1	2	3	4
My Support	1	2	3	4
My Diet	1	2	3	4
My Blood Sugars	1	2	3	4
Questions I Had about Diabetes	1	2	3	4
Habits	1	2	3	4
Pregnancy (Women only)	1	2	3	4
What Else	1	2	3	4

What other topics should be included in the calendar?

____

____

For any topics that were not clear (rated 1-2), what made the topic questions hard to understand or answer?

____

____

Ease of Use/Cognitive Benefits

On a scale of 1 to 5, with 1 being “Not at all” and 5 being “Very much” please tell me the number that best answers the question.

	Not at all ☆☆☆☆	Slightly ★☆☆☆	Somewhat ★★☆☆	Moderately ★★★☆	Very much ★★★★
1. How easy was it to complete the calendar overall?	1	2	3	4	5
2. Were the instructions clear?	1	2	3	4	5
3. Did you have trouble remembering information needed to complete the calendar?	1	2	3	4	5
4. In completing the calendar, did you learn anything about things that affect how well you are able to manage diabetes?	1	2	3	4	5
5. In completing the calendar, did you learn anything about what you need to manage diabetes better?	1	2	3	4	5
6. In completing the calendar, did you learn anything about things you could do to manage diabetes better?	1	2	3	4	5

7. Do you think the time periods used for the calendar (past week, past month, two and three months ago) were appropriate? If not, what time periods would you recommend using?

8. What other comments do you have about how easy the calendar was to complete? (i.e. What difficulties did you have in completing the calendar? What would make the calendar easier to complete?)

9. What comments do you have about what you learned by completing the calendar?

Communication Benefits

If you completed this calendar at your doctor's visit and shared it with your doctor, on a scale of 1 to 5, with 1 being "Not at all" and 5 being "Very much" please circle the number that best answers the questions.

	Not at all ☆☆☆☆	Slightly ★☆☆☆	Somewhat ★★☆☆	Moderately ★★★☆	Very much ★★★★
10. I would be interested in sharing the calendar with my doctor at my visit	1	2	3	4	5
11. The calendar would help me talk with my doctor about my diabetes	1	2	3	4	5
12. The calendar would help me remember things I need to ask my doctor to help me manage my diabetes	1	2	3	4	5
13. The calendar would help my doctor better treat my diabetes	1	2	3	4	5
14. The calendar would help my doctor provide better advice about diabetes that works for me	1	2	3	4	5

15. How else do you think the calendar would be useful during your doctor’s visit?

16. What other information should be asked about in the calendar?

17. What other comments do you have about sharing the calendar with your doctor during your doctor’s visit?

Appendix 3: Provider Event History Calendar Questionnaire

Thank you for taking the time to participate in the second phase of our study to better understand the needs of young adults (18-30 yrs) with diabetes. Based on discussions with patients and healthcare providers, we have designed a draft "Event History Calendar" for diabetes management of young adults. Event history calendars are designed to collect information from people about various relevant life topics/events over periods of time, depending on the purpose of the calendar.

The purpose of this calendar is to improve the information and care provided to young adult patients at diabetes appointments by presenting patients and providers a better picture of things going on in the patient's life that might affect diabetes management. Your answers to this questionnaire will help us decide how useful the calendar is and what revisions we need to make.

1) Please review each calendar as if these were from patients who had arrived at the clinic for a diabetes care appointment. Record the time it took you to review each calendar by noting the time at which you started and finished reviewing each calendar below.
You may write comments on the calendars as you review them.

Calendar 1 : Start time ______________ End time ______________
Calendar 2: Start time ______________ End time ______________
Calendar 3: Start time ______________ End time ______________

2) After reviewing all calendars, please complete the attached "Calendar Assessment Questionnaire."

3) Please return the completed questionnaire and the (3) calendars in the enclosed prepaid envelope.

THANKS FOR YOUR PARTICIPATION!

Calendar Assessment Questionnaire

Please answer the following questions.

On a scale of 1 to 4, with 1 being “Not at all relevant” and 4 being “Extremely relevant” please circle the number that best indicates how relevant you think each calendar topic is to improving a young adult patient’s care during his or her visit.

Calendar Topic	Not at all relevant	Somewhat relevant	Quite relevant	Extremely relevant
My Work/School	1	2	3	4
My Diabetes Supplies	1	2	3	4
My Activities/Social Life	1	2	3	4
Taking My Medications	1	2	3	4
Aches and Pains	1	2	3	4
Keeping Active	1	2	3	4
My Life Stress	1	2	3	4
My Support	1	2	3	4
My Diet	1	2	3	4
My Blood Sugars	1	2	3	4
Questions I Had about Diabetes	1	2	3	4
Habits	1	2	3	4
Pregnancy (Women only)	1	2	3	4
What Else	1	2	3	4

What other topics or questions should be included in the calendar?

____

____

____

1. Of all the topics in the calendar, please circle the <u>four most important topics</u> to include in a calendar

My Work/School
My Diabetes Supplies
My Activities/Social Life
Taking My Medications
Aches and Pains
Keeping Active
My Life Stress
My Support
My Diet
My Blood Sugars
Questions I had about Diabetes
Habits
Pregnancy
What Else
Other Please describe: ____

2. Of all the topics in the calendar, please circle the <u>four least important</u> topics to include in a calendar

My Work/School
My Diabetes Supplies
My Activities/Social Life
Taking My Medications
Aches and Pains
Keeping Active
My Life Stress
My Support
My Diet
My Blood Sugars
Questions I had about Diabetes
Habits
Pregnancy
What Else

On a scale of 1 to 5, with 1 being "Not at all" and 5 being "Very much" please circle the number that best answers each question below.

	Not at all	Slightly	Somewhat	Moderately	Very much
1. How easy was it to review the calendars overall?	1	2	3	4	5
2. How feasible would it be for you to implement use of the calendar during a clinic visit?	1	2	3	4	5
3. Do you think that the calendar would help you learn more about your patient's diabetes management challenges than you would during a typical visit?	1	2	3	4	5
4. Do you think that the calendar would help you learn more about other factors relevant to your patient's diabetes care than you would during a typical visit?	1	2	3	4	5

5. What other comments do you have about how easy the calendar was to review? (e.g. What difficulties did you have reviewing the calendar? What would make the calendar easier to review?)

6. Do you think the time periods used for the calendar (past week, past month, two and three months ago) were appropriate? If not, what time periods would you recommend using?

7. What comments do you have about information you may have learned in reviewing the calendars that might better facilitate diabetes care and management for younger adults?

On a scale of 1 to 4, with 1 being “Not at all” and 4 being “Very much” please circle the number that best reflects *how much you think the calendar would help you…*

	Not at all	Slightly	Somewhat	Moderately	Very much
8. Talk with your patient about his/her diabetes	1	2	3	4	5
9. Engage in more informed decision making for your patient’s diabetes management	1	2	3	4	5
10. Engage in more shared decision making with your patient regarding diabetes management	1	2	3	4	5
11. Provide better guidance to your patient about diabetes management relevant to your patient’s specific situation	1	2	3	4	5

12. How else do you think the calendar could be useful during a patient’s visit?

13. If the calendar were completed at a diabetes visit, which healthcare providers should review the calendar?

(Check all that apply)

☐Endocrinologist

☐Social Worker

☐Diabetes Nurse

☐Nutritionist

☐ Diabetes Educator

☐Other (list): ______________________

14. What other comments or suggestions about the calendar would you like to share?