

Before-Visit Questionnaire: A Tool to Augment Communication and Decrease Provider Documentation Burden in Pediatric Diabetes

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Abstract

Objective To develop and evaluate an electronic tool that collects interval history and incorporates it into a provider summary note.

Methods A parent-facing online before-visit questionnaire (BVQ) collected information from parents and caregivers of pediatric diabetes patients prior to a clinic encounter. This information was related to interval history and perceived self-management barriers. The BVQ generated a summary note that providers could paste in their own documentation. Parents also completed postvisit experience questionnaires. We assessed the BVQs perceived usefulness to parents and providers and compared provider documentation content and length pre- and post-BVQ rollout. We interviewed providers regarding their experiences with the system-generated note.

Results Seventy-three parents of diabetic children were recruited and completed the BVQ. A total of 79% of parents stated that the BVQ helped with visit preparation and 80% said it improved perceived quality of visits. All 16 participating providers reviewed BVQs prior to patient encounters and 100% considered the summary beneficial. Most providers (81%) desired summaries less than 1 week old. A total of 69% of providers preferred the prose version of the summary; however, 75% also viewed the bulleted version as preferable for provider review. Analysis of provider notes revealed that BVQs increased provider documentation of patients' adherence and barriers. We observed a 50% reduction in typing by providers to document interval histories. Providers not using summaries typed an average of 137 words (standard deviation [SD]: 74) to document interval history compared with 68 words [SD 47] typed with BVQ use.

Discussion Providers and parents of children with diabetes appreciated the use of previsit, parent-completed BVQs that automatically produced provider documentation. Despite the BVQ redistributing work from providers to parents, its use was acceptable to both groups.

Keywords

- ▶ questionnaires
- ▶ patient engagement
- ▶ documentation
- ▶ workflow
- ▶ outcomes

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Conclusion Parent-completed questionnaires on the patient's behalf that generate provider documentation encourage communication between parents and providers regarding disease management and reduce provider workload.

Background and Significance

Medical, social, and financial barriers faced by patients with diabetes may contribute to poor adherence to self-management plans.¹ Poor adherence, in turn, may result in complications such as renal, cardiovascular, and neurological diseases, vision loss, and premature mortality.^{2–4} Improving adherence to diabetes self-management requires identification of barriers,^{2,5} which may be time-consuming and difficult during short clinical encounters. Barrier identification can also be limited due to patient embarrassment, lack of awareness, communication difficulties, and other constraints.⁵ Research has demonstrated that as adherence increases, glycohemoglobin (A1c) decreases.⁶ The landmark Diabetes Control and Complications Trial showed that lower A1cs were associated with improved microvascular outcomes in patients.⁷ Moreover, previous work has shown that type 2 diabetes patients involved in an online disease management program achieved greater decreases in A1c at 6 months compared with patients receiving the usual care regimen.⁸ More patients in the intervention group achieved clinically meaningful A1c improvements versus the usual care group as well.⁸

While tools like Instant Medical History^{9,10} have facilitated clinical encounters in acute care settings and electronic questionnaires have been successfully used in outpatient pediatrics settings,¹¹ there is a paucity of evidence on BVQs in managing chronic diseases such as type 1 diabetes. In an adult diabetes population, patient submission of diabetes care plans electronically prior to clinic encounters resulted in a greater likelihood of medical regimen adjustment at the clinical encounter, suggesting the online submission reduced barriers to medication change at the visit thus improving patient care.¹² Determining strategies to capture information relative to barrier mitigation and adherence strategies is also important for follow-up to be effective. Computer-generated report systems with coded and free-text language have proved to be valuable in health care management and chronic disease follow-up in thyroid disease patients previously.¹³ Therefore, deploying BVQs that generate summary notes for physicians may be beneficial in the care of pediatric diabetes patients as well. It is essential that providers think beyond the current visit in chronic disease management as they are limited to a few brief patient encounters yearly to effect an outcome.

Objectives

In this exploratory study, we developed a *before visit questionnaire* (BVQ) as an electronic tool to collect information on interval history and adherence barriers, make information available to providers, and automatically generate a summary

for the visit note. Our aims were to (1) develop a BVQ tool, (2) use it in patient encounters in a pediatric diabetes clinic, and (3) evaluate its impact on barrier and adherence-related communication between parents and providers. We hypothesized that BVQs can improve communication about barriers and decrease documentation-related work. We also hypothesized that a tool that decreased provider effort to collect and document the interval history would improve documentation and result in more barriers being addressed.

Methods

Subjects and Setting

Patient and Parent Participants

Participants were recruited from the Eskind Pediatric Diabetes Clinic at Vanderbilt University Medical Center (VUMC), a large academic medical center in Nashville, Tennessee. The Eskind Pediatric Diabetes Clinic cares for approximately 2,000 patients from Tennessee and surrounding states. With VUMC Institutional Review Board (IRB) approval, letters were mailed to parents of patients from the Eskind Pediatric Diabetes Clinic that met the inclusion criteria inviting their participation through a hypertext link. Inclusion criteria required that patients: (1) had an established diagnosis of type 1 diabetes; (2) were <13 years old; (3) had a scheduled visit within 6 months of invitation receipt; (4) had parents or guardians able to read and provide informed consent; and (5) had access to a computer with Internet access. Parents who completed a BVQ received a \$15 gift certificate, and those who completed a postvisit survey received an additional \$5 gift certificate.

Provider Participants

We recruited physicians and nurse practitioners from the Vanderbilt Pediatric Endocrine Division, herein collectively called “providers.” Providers were apprised about the study, its aims, and their potential role in the study during a presentation at the Vanderbilt Weekly Pediatric Endocrine Lecture Series. Inclusion criteria were pediatric endocrinology attending physicians and nurse practitioners seeing pediatric diabetes patients at least once a week in the clinic. Trainees such as fellows and residents were excluded. Providers expressing interest in participating signed informed consent forms approved by the VUMC IRB prior to participation. Physicians received a \$50 gift card for sharing their feedback at the conclusion of the study.

Questionnaire Development

We developed the BVQ for this study to collect information about patient interval histories and adherence barriers in

children with type 1 diabetes (→ **Supplementary Appendix A**, available in the online version). We searched PubMed for articles on diabetes + adherence + barriers + pediatric to identify relevant themes to include in the questionnaire and investigated themes in adult diabetes literature to identify concepts that were generalizable to pediatrics. The BVQ includes questions about common barriers to pediatric diabetes care adherence as derived from our literature review and an assessment of provider clinical notes. BVQ items were reviewed for content validity through an iterative consulting process with content experts (pediatric endocrinologists, pediatric psychologists, and certified diabetes educators/nurse practitioners). Iterative changes ceased when no new recommendations were made. Five parents of patients with diabetes were asked to review the BVQ for clarity prior to deployment and offered no additional change suggestions. The final questionnaire included questions about demographics, medication regimen, interval history since the last appointment, adherence challenges, and barriers to diabetes care. Parents could also enter free text. The BVQ was implemented using REDCap¹⁴. Invitations to complete the BVQ included information on how to access the BVQ online and were sent via postal mail to eligible participants within 6 months prior to their next clinic visit. Families were requested to complete the BVQ up to 1 month prior to the clinic encounter. Following the mailed letter to parents, no messages were sent to remind parents to complete the BVQ. Discrete data fields completed in the BVQ autogenerated a summary note in prose intended for the provider documentation (→ **Supplementary Appendix C**, available in the online version). The summary note was finalized in REDCap when the questionnaire had been completed and pasted into the patient's electronic health record (EHR) by the research team (→ **Supplementary Appendix D**, available in the online version). The summaries were available to providers prior to a clinical encounter. Providers had the option of copying and pasting the summary notes into their documentation for the clinical encounter.

After an encounter, parents were invited to complete a postvisit survey created in REDCap to determine how they perceived the BVQ and its effect on the clinical encounter (→ **Supplementary Appendix B**, available in the online version). The survey asked if the BVQ prepared them for the visit and if it improved the encounter. Response options were *strongly disagree*, *disagree*, *agree*, and *strongly agree*. Participants were asked if discussion of their primary medical and primary psychosocial barriers would have occurred without the aid of the BVQ (*yes*, *no*, and *unsure*). An internal research team analyzed free-text comments from parents in the questionnaire.

Provider Note Analysis

We reviewed provider clinical encounter notes for each of the participating patients using two sets of notes. *Intervention notes* were clinic visit notes written by the provider after the patient's parent had completed a BVQ. BVQ summary notes were generated from those completed BVQs and made available for providers to paste and incorporate into their

clinic note. Some intervention notes included an incorporated BVQ summary if the provider chose to paste that summary content into their note. Some intervention notes did not include the BVQ summary if the provider did not paste that content. *Control notes* were clinic visit notes for the same patients, but from encounters before the patient enrolled in the study and before a BVQ was completed. We assessed control notes for the two most recent encounters prior to the intervention if available. If only one encounter note had been created prior to the intervention, we used it as the sole control note.

Provider notes were coded using Vanderbilt PYBOSSA (Python Berkeley Open System for Skill Aggregation).¹⁵ PYBOSSA is an analytic framework designed to navigate clinical chart reviews. It includes an architecture for storing and displaying sensitive data, and developing tools to support crowdsourcing for analysis of large complex datasets such as EHR notes. The length and volume of the provider notes lent itself well to the PYBOSSA crowdsourcing method for theme identification. The themes used in codifying the elements of the provider notes were developed from the same literature review method that was conducted to determine themes for the BVQ using common constructs for pediatric diabetes care barriers and adherence challenges. The PYBOSSA system stored de-identified notes and displayed them to study workers, allowing them to snip sections of results and code them according to the scheme for adherence and barriers to adherence. Coding results were reviewed by the principal investigator (PI) and five medical student research team members. Final codes were assigned by majority decision of the group. We compared the frequency with which adherence challenges and barriers were applied in intervention versus control notes.

Word count was conducted using Microsoft Word 2016's word count feature. Number of words typed was used as a surrogate outcome measure for documentation burden. Specifically, we counted the words typed by a provider in the history of present illness (HPI) section in the patient's interval summary. Research team members reviewed the HPI of final progress notes and identified HPIs containing components pasted from the BVQ-generated summary. Word count was calculated as the number of words typed by the provider minus words from the pasted BVQ summary. The number of words typed in the HPIs that contained pasted summary information was compared with word counts in HPIs that did not contain any text from the BVQ-generated summary.

Provider Interviews

All participating providers completed one-on-one interviews on using system-generated summaries to prepare for clinical encounters and their documentation process. Audio recordings of the interviews were transcribed verbatim and verified. Files containing the transcribed interview notes were imported into Dedoose (Version 7.6.6), a qualitative data analysis software application.

Provider statements were mapped to a theoretical model of provider views about the note's efficacy as a clinical

decision support tool. Critical concepts in this model include (1) right information, (2) right recipient, (3) right intervention format, (4) right communication channel, and (5) right time in the workflow. Data were analyzed with Dedoose using a grounded theory approach, including line-by-line coding followed by axial coding to understand relationships of key concepts to one another. Focused coding mapped provider opinion concepts on the usefulness of the BVQ summaries as a decision support instrument. Three researchers trained in qualitative data analysis identified themes across notes and coded/analyzed the data. These themes were used to create a key with codes for each theme, which was used to code interview transcripts. The PI and a second author coded all interview transcripts. Final codes between assignments were compared with identified conflicts, which were reconciled by discussion. A third team member occasionally broke ties to resolve disagreements.

Statistical Analyses

Data were analyzed using R Studio software for Windows and Stata 12.1 (StataCorp LP). We reported means and standard deviations (SDs) for continuous variables and counts and frequencies for categorical variables. A chi-squared test was used as a trend in proportions test. Wilcoxon and Pearson tests were used for testing differences in demographic statistics between the participants in the study and those who did not participate. We used logistic regression models with the Huber–White method to adjust the cluster

effect within provider for adherence, barrier, adherence plan, and barrier plan from the provider note coding. An ordinal logistic regression model with the Huber–White method calculated a total score, which was the sum of scores for adherence, barrier, adherence plan, and barrier plan. A Wilcoxon test was used to test the difference in additional word usage for word-count comparisons.

Results

Patient and Parent Characteristics

A total of 321 parents met the study's eligibility criteria. Among these, 97 (30%) agreed to log into the system and participate in the study. Seventy-three (22%) completed the questionnaire and had a subsequent clinical encounter. ▶Tables 1 and 2 show the demographic and clinical characteristics of patients and parents who participated in the study. The mean age of patients was 9.1 years (SD: 2.9 years), while that of parents was 38.9 years (SD: 5.8). Fifty-eight percent of the patients were female, while 92% of parents were female. The mean patient A1c value was 8.0% (SD: 1.0; target: <7.5%). The average time since the diabetes diagnosis was 3.4 years (SD: 2.3). ▶Table 1 also shows the demographic and clinical characteristics of the patients whose caretakers were invited to complete the questionnaire but did not respond (nonresponders). There were statistically significant differences in the income, race, and A1c values of the two groups ($p < 0.05$ for each group).

Table 1 Demographic and clinical characteristics of children of respondents and nonrespondents in the BVQ study

Variable	BVQ children (n = 73) Mean [SD] or n (%)	Children with nonrespondent parents (n = 248) Mean [SD] or n (%)	p-Values
Age	9.1 [2.9]	9.2 [2.6]	0.539
Female	42 (58)	121 (49)	0.183
Race (multi-select)			0.008
Caucasian	71 (97)	189 (76)	
African American	4 (5)	33 (13)	
Others		26 (11)	
Pump user	31 (42)		
Diabetes duration (y)	3.4 [2.3]		
A1c	8.0 [1.0]	8.3 [1.6]	0.025
Household income			0.044
<\$20,000	3 (4)	0 (0)	
\$20,001–\$40,000	7 (10)	2 (1)	
\$40,001–\$70,000	19 (26)	171 (69)	
>\$70,001	44 (60)	75 (30)	
Insurance			0.001
Private	55 (75)	136 (55)	
Medicaid	18 (25)	112 (45)	

Abbreviation: BVQ, before visit questionnaire.

Note: Children of nonrespondents are pediatric diabetes clinic patients who were invited to join the BVQ study but did not participate. Demographic information for children of nonrespondents was collected through medical chart review.

Table 2 Demographic and clinical characteristics of study BVQ parent respondents

Variable (n = 73)	BVQ parents Mean [SD] or n (%)
Age	38.9 [5.8]
Female	67 (92)
Race (multi-select)	
Caucasian	71 (97)
African American	2 (3)
Parent education	
High school or GED	7 (9)
2-year college	21 (29)
4-year college	26 (36)
Master's degree	14 (19)
Doctoral or professional degree	5 (7)
Parent relationship to child	
Mother	66 (90)
Father	6 (9)
Grandparent	1 (1)
Parent marital status	
Single	6 (8)
Married	66 (91)
Long-term relationship	1 (1)

Abbreviation: BVQ, before visit questionnaire.

►Fig. 1 shows the top medical and psychosocial barriers and adherence challenges facing parents who completed the survey. The top medical barriers were “how certain foods affect blood sugar,” “what to do when sick,” and “how exercise affects blood sugar.” The top psychosocial barriers

were “keeping a close eye on things when busy,” “option for free-text response,” and “cost and finances.”

Narrative text responses about barriers were provided by 33% of participants; 55% of responses were already mapped to medical or psychosocial barriers in the system, particularly “arguments with child about diabetes.” The main free-text responses that did not map to existing barriers were concerns about hypoglycemia and parents feeling overwhelmed with the daily rigor of the regimen.

Provider Characteristics

All sixteen providers working in the Vanderbilt Eskin Pediatric Diabetes Clinic practice participated in the study. The mean age for providers was 45 (SD: 11) years, with 12 (SD: 11) average years of practice. Most were female (69%). Providers attended the clinic an average of 4 half-days per week (SD: 2). When asked about typing notes during an encounter, 56% stated that they always typed while in the room with the patient, 31% stated they sometimes did, and 13% stated they never did.

Providers who documented in the room stated that capturing information immediately was more efficient than writing notes on paper and typing them later and easier than recalling it afterwards. Providers preferring not to document in the room noted that doing so could reduce efficiency and patient engagement. For this group, typing a clinic note accurately during an encounter was difficult, as was maintaining patient engagement while working in the EHR.

Qualitative Analysis of Provider Perspectives on the Generated Summaries as Clinical Decision Support

As noted in the Methods section, we examined the following categories:

- **Right information:** Thirteen of the 16 (81%) providers desired that summaries be generated <7 days prior to

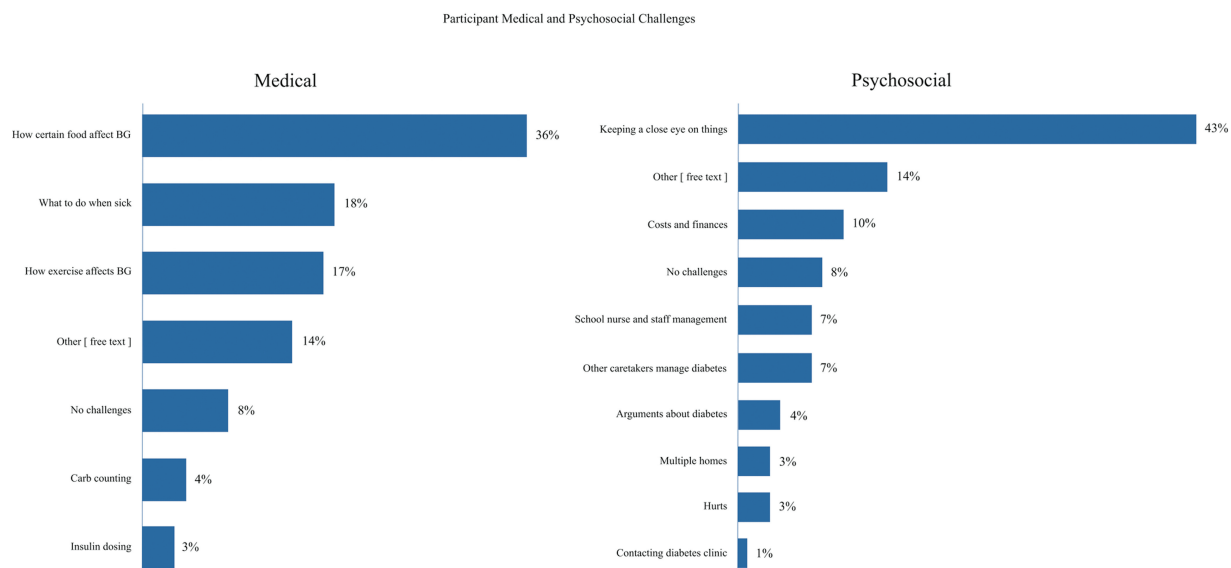


Fig. 1 Medical and psychosocial barriers and adherence challenges selected by participants. BG, blood glucose.

the visit, 2 of 16 (12%) were willing to accept summaries ≤ 14 days old, and 1 of 16 (7%) would use a generated summary ≤ 4 weeks old. Ideas like “accurate” and “true and current” were used to describe the relevance of the generated summary in association with its age. Providers were concerned that completing the BVQ too far in advance of the encounter was subject to inaccuracy due to changes over time.

- **Right person:** All providers found barrier information to be useful and noted that the time to acquire it on their own could be prohibitive. One provider stated that having the information provided was particularly helpful given time constraints that would otherwise prohibit them from a more thorough review: “[we do] not often get into this... in the short time that we have.”
- **Right intervention format:** 11 of 16 (69%) of providers stated that the paragraph version of the note was an optimal format for communicating its content externally, as when sending their consultation note to a referring provider. One provider stated, “the role of sentences is to mimic conversation between two individuals. And [...] it would be a more appreciated version for a primary care physician or a referring physician. [...] I would prefer to get something like this... rather than a bulleted thing. It [...] lends a more personal touch.” A total of 12 out of 16 (75%) stated that a bulleted version would be optimal for self-review because the data could be easily scanned and the format would “save time.”
- **Right communication channel:** 15 of 16 (94%) of providers desired a feature for auto-importing the generated summary into their documentation to make it available for review and editing. Some providers expressed frustration about forgetting to access the summary before a clinical encounter, with one stating, “[I was] kicking myself when I noticed it was there and I didn’t use it.” Although the generated summary was visible in the patient’s chart, providers could overlook it because it was not directly linked to their documentation.
- **Right time in the workflow:** All providers found access to barrier information before a patient encounter useful as a way of preventing “surprises” and being caught “off guard.” One provider stated it would be particularly helpful in a pediatric patient to “find out if they’re pregnant before you go in.”

Provider-Generated Notes

Intervention and Control Note Documentation

► **Table 3** shows documentation frequency of barriers, adherence challenges, and plans to address them in 204 provider notes.

Adherence Documentation and Plans to Address

Adherence Problems from Intervention

Of the 73 intervention notes, 18 (25%) described adherence problems compared with 17 of 131 (13%) of the control notes, a difference that was statistically significant ($p = 0.034$). Plans to address adherence problems were noted in 14 of 73 (19%) of the intervention notes compared with 14 of 131 (11%) of control notes ($p = 0.091$).

Barrier Documentation and Plans to Address Barriers from Intervention

Barriers were coded in 14 of 73 intervention notes (19%) compared with 19 of 131 (15%) of control notes ($p = 0.385$). Plans to address these barriers were noted in 6 of 73 (8%) intervention notes and 15 of 131 (11%) of control notes ($p = 0.46$).

► **Table 4** shows barriers and adherence challenges in the 204 provider notes, comparing intervention notes that incorporated the generated interval summary to a cluster of all notes (both intervention and control notes) that did not include the generated summary, as a secondary analysis.

Adherence Documentation and Plans to Address

Adherence Problems When BVQ Summary Incorporated

Seven of 13 (54%) notes that incorporated the generated interval history noted adherence problems, compared with 28 of 191 (15%) control notes that did the same ($p < 0.001$). Plans to address adherence problems were noted in 5 of 13 (38%) notes with the interval history compared with 23 of 191 (12%) notes without ($p = 0.024$).

Barrier Documentation and Plans to Address Barriers When BVQ Summary Incorporated

Barriers were coded in 5 of 13 (38%) notes that did incorporate the generated interval history, compared with 28 of 191 (15%) control notes that did not incorporate it ($p = 0.007$). Plans to address these problems were noted in 3 of 13 (23%)

Table 3 Coding results for provider intervention and control notes

	Intervention ($n = 73$) Documented (%)	Control ($n = 131$) Documented (%)	Test statistic
Adherence	18 (25)	17 (13)	$p = 0.034$
Adherence plan	14 (19)	14 (11)	$p = 0.091$
Barrier	14 (19)	19 (15)	$p = 0.385$
Barrier plan	6 (8)	15 (11)	$p = 0.467$

Note: Adherence challenges and barriers documented in provider intervention and control notes. Intervention notes were written by the provider for research patients after they completed a BVQ. Control notes were written by the provider for the same research patients for encounters prior to the patient’s BVQ enrollment and completion of the BVQ questionnaire.

Table 4 Coding results for provider notes with and without generated summary incorporated

	Incorporation of generated history (<i>n</i> = 13) Documented (%)	No incorporation of generated history (<i>n</i> = 191) Documented (%)	Combined (<i>n</i> = 204) Documented (%)	Test statistic
Adherence	7 (54)	28 (15)	35 (17)	$p < 0.001$
Adherence plan	5 (38)	23 (12)	28 (14)	$p = 0.007$
Barrier	5 (38)	28 (15)	33 (16)	$p = 0.024$
Barrier plan	3 (2)	18 (9)	21 (10)	$p = 0.117$

Note: Adherence challenges and barriers documented in notes that incorporated the generated interval history after patient completed a BVQ compared with all notes for encounters prior to the patient's BVQ enrollment and completion.

notes with the history compared with 18 of 91 (9%) notes without incorporated interval history ($p = 0.117$).

Note Word Count

When providers included summaries generated by the BVQ in their notes, the average length of the HPI was 68 words (SD: 47) typed by the provider, excluding content copied from the summary. When BVQ summaries were not included, the average HPI length was 137 (SD: 74) typed words ($p = 0.003$; ►Fig. 2).

Parent Participant Postvisit Evaluation

Sixty-eight of the 73 BVQ participants completed the post-visit questionnaire. Of these, 80% agreed (35%) or strongly agreed (45%) that the BVQ prepared them better for the visit, with 79% agreeing (38%) or strongly agreeing (41%) that the BVQ improved the visit. While the majority (69%) indicated that they would have discussed their primary medical bar-

riers with their provider, 31% were either unsure (29%) or would not have (2%) discussed their barriers without the BVQ (►Fig. 3).

Discussion

Eliciting barriers to diabetes self-management can help health care providers to develop strategies to overcome them. We created a parent-facing BVQ that collected information about histories and barriers and generated a summary note for the provider. This study demonstrated that BVQs were accepted by providers and parents of patients with pediatric diabetes, increased documentation of adherence problems, barriers, and plans to address them, and may have facilitated discussion about challenges that could have gone unaddressed otherwise in approximately 30% of patients. This study is unique in that it addresses the use of a BVQ as part of chronic disease management, while other studies with patient questionnaires focus on assisting data collection in acute care settings.^{9,16–19}

In this study, most parents agreed that the BVQ had a positive impact on their clinical encounter via identifying and communicating barriers prior to the clinic visit. This process may be augmented by using BVQ as a tool to log and track the course of a patient's concerns leading up to each clinical encounter. By capturing most barriers in a structured way, the BVQ may benefit overall patient care by facilitating

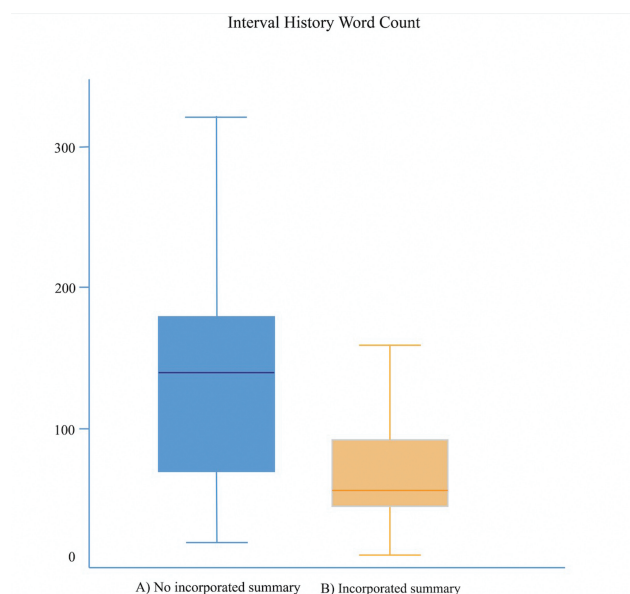


Fig. 2 Average number of words typed by providers in the interval history portion of the clinic note when (A) generated summaries were not incorporated in the documentation compared with number of words typed and when (B) generated summaries were not incorporated in the documentation.

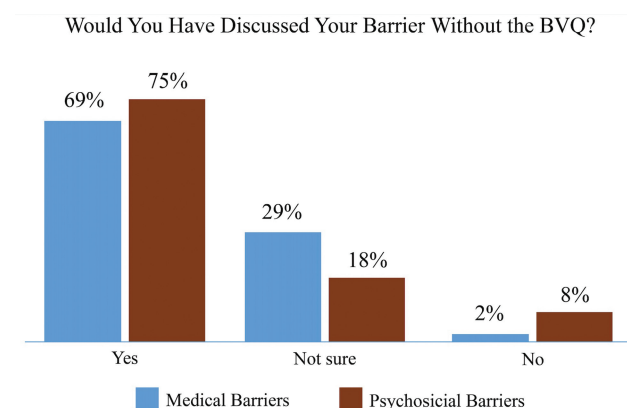


Fig. 3 Postvisit response from participants: BVQ facilitation of barrier discussion. BVQ, before visit questionnaire.

connections with appropriate professionals, such as a social worker for patients describing financial barriers. Additionally, collecting barrier and interval history information longitudinally will enable medical teams to evaluate how effectively patients' barriers are being addressed, determine measures that can be taken to anticipate barriers and improve adherence, and inform early interventions. This approach could also serve as a platform for patient education and shared decision making by giving patients access to educational modules based on responses entered.

Moreover, this study highlights the relevance of patient communication using free-text comments: one-third of parent participants provided free-text responses regarding barrier concerns, despite that 55% of those could be mapped to available selection options. Future work can explore the content of the free-text comments to better understand why participants did not choose similar available options. Sentiment and polarity analysis of free-text responses can also be explored to alert the medical team regarding patient or parent sentiments of concerns expressed.

Among providers, the generated interval summary was well received and seen as a benefit. Timeliness of the information was an important feature. Given that accuracy in older summaries could be questionable, the majority of providers (81%) desired summaries less than 1 week old. A majority also desired a right-work-flow-channel feature that would auto-import a highly visible summary into their clinical notes. Providers who incorporated the summary into their notes were statistically more likely to document barriers and plans to address them. Future BVQ iterations might incorporate prompts in the note's assessment and plan section to encourage documentation of plans for each barrier. Providers who preferred to document in the room as well as those who preferred not to could benefit from a workflow that presents an interval summary for a patient prior to a clinical encounter. Providers who copied the generated summary into their notes typed 50% fewer words in the HPI, as the summary already provided the content. Hence, our data suggest that both groups of providers may find that less documentation is required since relevant information would be captured before the encounter. The perspective of providers who did not document during the encounter may evolve if this tool is leveraged as a discussion aid facilitating patient engagement. In this sense, the BVQ could help providers who are concerned about EHRs interfering with patient engagement. Furthermore, providers did not express concerns about missing patient issues after BVQ use as they still had the opportunity to discuss any issues with the parents during the encounter. This method allowed the parent to have initial consideration about their concerns and share them with the provider, thus allowing these concerns to be at the forefront of conversation.

Finally, regarding the format of the interval summary (prose vs. bullets), most providers preferred the prose version (69%) as the output of their note for others to view as that tends to be more reflective of a thorough written note.

However, 75% also viewed the bulleted version as preferable for self-review to easily pick up information. Fortunately, electronic systems can render information to suit a user's needs and a toggle feature can be incorporated to change views between prose and bullets according to the user's preferences.

Limitations

Our study has several limitations. Data were obtained from a single subspecialty clinic at a single medical center, yielding a small sample size. Therefore, external validation and a larger sample would be necessary in future studies to understand the broader applicability of this approach. There were notable differences between our respondent and nonrespondent populations by race, income, and glycemic control, all of which may further limit the generalizability of the outcomes. Because the BVQ was administered online, the study design may have selected for individuals with Internet connectivity. Ultimately, porting the BVQ to a mobile device will be important to execution at scale to ensure patient inclusion regardless of computer and Internet access. Future work may consider deploying the BVQ through the portal of the EHR system to integrate patient documentation and concerns directly into their physician's electronic chart as well as increase accessibility of the BVQ to patients.²⁰ The quasi-experimental and exploratory nature of the study also poses limitations. Examining communication about barriers based on provider documentation may not have been the optimal method for assessing the impact of the BVQ on patient-provider communication. Conversations about barriers might have occurred during the clinical encounter without the provider fully documenting that exchange. However, documentation has an important role in communication and as evidence of work done. Audio or video recording of clinical encounters may provide a more sensitive and specific means of capturing this information. Collecting long-term follow-up data from patients might be useful to assess how well a provider addressed barriers and their effects on clinical outcomes, such as A1c values. Extension to other medical conditions will also motivate initiatives for incorporating patient-generated content into clinical documentation. EHR systems that support data collection that can be integrated into existing portals and clinical notes will be important in the scalability of this methodology.

This approach shares a portion of the documentation effort between providers and parents in a coproduction model. While consumers are already used to doing more and more work that organizations previously did for them (e.g., self-checkout in grocery stores, updating demographic information for banks), the cost of the added effort may have been too high for some parents. It is possible that some parents may have encountered structural barriers to BVQ access, and acknowledgment of this digital divide is of particular importance in future implementations to ensure we do not overlook the barriers of individuals that may have the greatest needs. For parents who participated in our study, the improved interactions with the providers may have been a net-positive trade-off, but this idea must be

further studied in an environment without the incentives of gift cards. Finally, while parents of children with diabetes were consulted for assessing BVQ clarity before deployment, future BVQ iterations might consider including parent input in the design of the questions. It was notable that the intervention elicited more documentation of adherence concerns compared with barriers. This may be a function of inherent challenges in the self-identification of barriers from the limited list generated by the study team. Leveraging the survey design process in collaboration with parents may help identify additional relevant barriers that could be elicited in the BVQ.

Our data suggest that providers may require less documentation when using the BVQ autogenerated summaries. However, with a larger sample size, one may find that providers feel obliged to edit the autogenerated note, add details not mentioned in the HPI section, or document more in the assessment and plan to address each item in the autogenerated summary. Considering only a fraction of providers copied the autogenerated note into the provider notes, the added importing step may be a limitation. Providers may benefit from having the autogenerated note automatically appear as a provider's note and electing to "opt out" and delete the note if they do not find it helpful rather than "opt in" to its inclusion. Lastly, using the number of words providers typed in the interval summary as a surrogate measure of documentation burden does not factor in the time and effort providers spent reviewing or editing their notes. Thus, future work may utilize a larger sample and measure time spent on this section looking at elements such as elapsed time and keystrokes rather than words typed to estimate the differences in providers' efforts.

Conclusion

Parent-completed BVQs in the form of electronic questionnaires may change the way parents and providers communicate about a patient's care management. Although this study evaluated the utility of BVQs completed by parents on behalf of minor patients, in the future this method could be extended to incorporate BVQ self-completion by adolescent and adult patients as well. EHR systems offering BVQs can help providers address more barriers and improve patient engagement and provider efficiency. This area is rich for disruption, and our simple strategy demonstrated efficacy in terms of adherence and barrier-related communication and acceptability to patients and providers. Patients may contribute to their medical records using BVQs, and they may accept the added effort because they believe that the process benefits them. With new regulations that promote clinical documentation sharing with patients, patients may appreciate seeing their concerns acknowledged as part of their provider's documentation.²¹ Although BVQs may already be in use in some medical disciplines, our approach demonstrates its usefulness before clinic encounters to improve care for patients with chronic diseases. It is time to revisit the standard use of paper clipboard forms used for this purpose. We have demonstrated that a new workflow

of electronic BVQs may improve communication about adherence and barriers in pediatric patients with chronic diseases and decrease documentation work for providers, leading to improvements in patient engagement and overall care.

Clinical Relevance Statement

BVQs have the potential to increase patient engagement, improve communication about health barriers, and automatically produce a portion of provider documentation. BVQs offer a promising alternative approach to standard provider-driven documentation.

Multiple Choice Questions

1. A critical component of the model of clinical decision support is:
 - a. A stochastic analysis describing a sequence of possible events.
 - b. Information present at the right time in the workflow.
 - c. Automatic manipulation of natural language.
 - d. A formatting system for displaying material retrieved via the Internet.

Correct Answer: The correct answer is option b. The five rights of the clinical decision support model include (1) right information, (2) right recipient, (3) right intervention format, (4) right channel, and (5) right time in the workflow. This model can be used to evaluate the effectiveness of tools that facilitate decision-making.

2. Before visit questionnaires (BVQs) improve the quality of the clinic visit by:
 - a. Statistically increasing the documentation of adherence and barriers.
 - b. Reducing the parent's effort in preparing for the visit.
 - c. Increasing the amount of typing a provider generated.
 - d. History information older than 1 month.

Correct Answer: The correct answer is option a. BVQs increase the documentation of adherence issues and plans to improvement as well as barriers. The cost includes more work for the parent in advance of the visit. BVQs reduce the amount of typing by providers and by limiting the time frame to less than 1 month provide relatively new information.

Protection of Human and Animal Subjects

This study was reviewed and approved by the Institutional Review Board at Vanderbilt University Medical Center.

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Conflict of Interest

None declared.

References

- 1 Kumah-Crystal YA, Hood KK, Ho YX, et al. Technology use for diabetes problem solving in adolescents with type 1 diabetes: relationship to glycemic control. *Diabetes Technol Ther* 2015;17(07):449–454
- 2 Mulvaney SA, Hood KK, Schlundt DG, et al. Development and initial validation of the barriers to diabetes adherence measure for adolescents. *Diabetes Res Clin Pract* 2011;94(01):77–83
- 3 Irvine AA, Saunders JT, Blank MB, Carter WR. Validation of scale measuring environmental barriers to diabetes-regimen adherence. *Diabetes Care* 1990;13(07):705–711
- 4 Odegard PS, Gray SL. Barriers to medication adherence in poorly controlled diabetes mellitus. *Diabetes Educ* 2008;34(04):692–697
- 5 Grant RW, Altschuler A, Uratsu CS, et al. Primary care visit preparation and communication for patients with poorly controlled diabetes: a qualitative study of patients and physicians. *Prim Care Diabetes* 2017;11(02):148–153
- 6 Hood KK, Peterson CM, Rohan JM, Drotar D. Association between adherence and glycemic control in pediatric type 1 diabetes: a meta-analysis. *Pediatrics* 2009;124(06):e1171–e1179
- 7 Nathan DMDCCT/EDIC Research Group. The Diabetes Control and Complications Trial/epidemiology of diabetes interventions and complications study at 30 years: overview. *Diabetes Care* 2014;37(01):9–16
- 8 Tang PC, Overhage JM, Chan AS, et al. Online disease management of diabetes: engaging and motivating patients online with enhanced resources-diabetes (EMPOWER-D), a randomized controlled trial. *J Am Med Inform Assoc* 2013;20(03):526–534
- 9 Pierce B. The use of Instant Medical History in a rural clinic. Case study of the use of computers in an Arkansas physician's office. *J Ark Med Soc* 2000;96(12):444–447
- 10 Wenner AR, Ferrante M, Belser D. Instant Medical History. *Proc Annu Symp Comput Appl Med Care* 1994;•••:1036
- 11 Hanmer J, Ray KN, McCracken P, et al. Uptake of an integrated electronic questionnaire system in community pediatric clinics. *Appl Clin Inform* 2021;12(02):310–319
- 12 Grant RW, Wald JS, Schnipper JL, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. *Arch Intern Med* 2008;168(16):1776–1782
- 13 Nordyke RA, Kulikowski CA. An informatics-based chronic disease practice: case study of a 35-year computer-based longitudinal record system. *J Am Med Inform Assoc* 1998;5(01):88–103
- 14 Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42(02):377–381
- 15 Ye C, Coco J, Epishova A, et al. A crowdsourcing framework for medical data sets. *AMIA Jt Summits Transl Sci Proc* 2018; 2017:273–280
- 16 Slack WV, Hicks GP, Reed CE, Van Cura LJ. A computer-based medical-history system. *N Engl J Med* 1966;274(04):194–198
- 17 Quaak MJ, Westerman RF, van Bommel JH. Comparisons between written and computerised patient histories. *Br Med J (Clin Res Ed)* 1987;295(6591):184–190
- 18 Porter SC, Silvia MT, Fleisher GR, Kohane IS, Homer CJ, Mandl KD. Parents as direct contributors to the medical record: validation of their electronic input. *Ann Emerg Med* 2000;35(04):346–352
- 19 Dugaw JE Jr, Civello K, Chuinard C, Jones GN. Will patients use a computer to give a medical history? *J Fam Pract* 2000;49(10):921–923
- 20 Wald JS, Middleton B, Bloom A, et al. A patient-controlled journal for an electronic medical record: issues and challenges. *Stud Health Technol Inform* 2004;107(Pt 2):1166–1170
- 21 Okoro AO. Preface: the 21st century cures act—a cure for the 21st century? *Am J Law Med* 2018;44(2-3):155