Adolescents with Diabetes: Opinions of Health Education Documents

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20 minute presentation requested
Abstract

This session presents qualitative findings regarding adolescent’s opinions on diabetes health-information material. Four 17-year-old girls with diabetes were each shown three different versions of diabetes education documents and answered questions about those documents. Interviews and observations suggest that 1) participants want current and in-depth information that is presented clearly and concisely, 2) participants consider organizers important, because they would be searching for specific information in the document, 3) participants consider visual elements of the material important as information containers, attention grabbers, and as indicators of the intended audience, 4) participants desire material that is individualized to their situation. Based on these findings, the “ideal document” for these participants is described.
Presentation Outline

Introduction
- Adolescent development
- Diabetes and adolescents
- Health documents for adolescents

Method
- Documents – Three versions a) paper copy created by a physician, b) booklet created for children, c) booklet created for adults
- Participants – Four 17-year-old females who have diabetes.
- Interviews – Conducted during clinic visit. Parents present during two interviews. Interview guide approach was used.
- Analysis – Audiotapes transcribed. Categories created based on research question and emerging trends. Both across and within participant results were considered.

Findings
- Participants want current and in-depth information, but presented clearly and concisely.
- Organizers are considered important. Three of four participants looked at the index. They considered organization important because they would be using the material to find specific information (not to browse).
- Visual elements of the material were considered important as containing information, grabbing attention, and conveying the intended audience.
- Participants desire material that is individualized to their situation.

Implications
- The ideal document? (a proposal, based on these findings)

Possible discussion questions:
- What are good methods of gathering information from adolescents about their perspectives?
- What are some of the development issues that make adolescents a unique audience?
Introduction

For approximately 125,000 youth under age 20, managing diabetes is a part of growing up. For teenagers with the illness, responsibilities of self-care coincide with the normative developmental tasks of seeking identity striving and independence. Health care professionals often consider this population challenging, citing compliance with medical needs as problematic. Regulation of blood sugar levels through diet, daily testing and injections have short and long term health implications for those with diabetes.

Diabetes education is thought to play an important role in health success. There appears to be little information on how to target adolescents regarding chronic health conditions, but work by Karen Schriver (1997) provides valuable insight into how design features may influence effectiveness of such materials. Schriver gathered one hundred brochures intended for adolescent population from health agencies, and selected a subset of brochures regarding drug and alcohol prevention. Then, in focus groups, surveys, one-to-one interviews, and think-aloud reading protocols, 297 students evaluated the material. Schriver found that most of the brochures appeared to be ineffective at meeting their goals. Among her observations, adolescents frequently had negative comments regarding the brochures that were unrelated to the actual content, but how it was presented. For example, they often had formed strong opinions of the people who created the brochures based on the types of images and wording used. Schriver concludes that the designer will need a keen understanding of the teen audience in order to anticipate how diverse audiences may construct messages directed to them.

The current study set out to examine how adolescents with diabetes perceive health education material. What features might they consider most important? What design characteristics might serve to draw them in, or push them away?
Methods

Qualitative methodology seemed best suited for the exploratory nature of this work. The sequence in this study followed those suggested by Kvale (1996) for designing and implementing an interview study:

*Thematizing:*

The purpose of this study was to examine adolescent’s perceptions of educational documents related to chronic illness.

*Designing:*

Consent was obtained from the university human subjects committee. My plan included gathering three different types of diabetes education documents, and having teens with diabetes look at them during a clinic visit. I was interested in their opinions on how what features were most important, how effective different styles of documents are, how these documents are designed, and by whom.

I gathered documents by visiting two local physician offices that treat diabetes and asking what they might use with their adolescent population. I contacted a large diabetes clinic and gained permission to conduct the study during a regular clinic day.

I created a list of interview questions, but allowed for flexibility in the wording and sequence. This “interview guide approach” has the advantage of allowing more informality than a standardized interview, although it may make analysis more difficult because participants may not all respond to identical questions (Patton, 1990).

The following questions were included on my list:

- What is good, bad about this material?
- What is its goal?
- When would you look at it, use it?
- Would it be effective?
- Who is it intended for?
- Who do you think created it?
• How should this type of material be created?
• What *should* it look like?

*Interviewing:*

Interviews took place during the adolescent’s scheduled clinic visit. The researcher was present for 3 hours during clinic hours, and physicians identified eligible participants from those who were at the clinic for appointments during those hours. A physician told the teen patients and parents about the researcher, and asked for initial permission for the researcher to describe the study. The physician then notified the researcher, who entered the room, described the study, and obtained signed consent from participants and their parent.

An audio recorder was set on the table and turned on, and the researcher removed one of the documents from its envelope. The participant was encouraged to look through the document, and interview questions were presented. This same procedure was repeated with the other two documents.

Some, but few, notes were taken by hand during the interview. Most were references to page numbers of examples referenced by participants. Parents were present during two of the interviews, and just participant and researcher were present during the others. Interviews ranged from 10 – 15 minutes. On one occasion the interview was wrapped up more quickly than planned because a physician was waiting to see the participant.

*Transcribing:*

Audio tapes and written notes were transcribed and entered into a word processing document.

*Analyzing:*

Text files of transcriptions were imported into QSR NUD*I*ST NSR qualitative analysis software. After reviewing the data several times, initial categories (nodes) were created. Thematic comments, which could consist of one or more sentences, were considered the units of analysis. Each was either placed into an existing category, or led
to creation of a new category when needed. Categories were refined and adjustments made over approximately 10 visits to the data. This approach served best to identify trends among the four participants. A second methodology was used to explore individual differences that might exist. A 3 x 3 matrix was created, to represent all possible combinations of participants and document option. Key words and/or observations was placed in each cell from that participant/document event. This allowed a manageable, visual framework for comparing participants in each condition and across the entire interview.

This work is still considered exploratory and in-progress. And although the following categories are not thought to be exclusive or exhaustive, analysis-to-date provides several findings that appear valuable to those interested in health-related document design for youth.
Results

It would not be fair to suggest that all participants had identical points of view. Interviews and observations revealed several unique perspectives in addition to the commonalities found among them.

- The level of opinion and attention to detail varied among participants. For example, one participant was eager to point out a typo she found in one of the documents. In contrast, when asked her first impression of the same document, another participant replied, “I don't know, I wasn't really thinking about it”.
- While three participants thought adult photographs should be included in the document, one felt that only teens should be represented.
- General consensus seemed to exist regarding a desire for information specific to their particular case, but participants varied somewhat on the value of general information. For example, one participant said that people her age will be looking for “something specific” when they use the document, but another suggested that including current information would help her talk to her doctor in a more informed manner.
- Although participants were all the same age, the importance placed on independence and respect for their age may have varied among them. For example, one participant stated in her interview, “…it looks more sophisticated and more for somebody who's going to be doing this on their own”, and about another document ”because, the pink panther one is like, they're kind of talking down to me”. This participant would vote to take out photographs of adults if the brochure was intended for teenagers. Incidentally, this participant was one of two whose parent sat in the waiting area during the appointment. This high level of independence was not seen in all participants. Another, for example, had her mother present during the interview and said at one point, "I don't talk much".

Given that differing perspectives such as these exist, a number of trends were identified in the interviews. Among them are:
**Quality of Information**

In general, participants wanted information that goes into sufficient depth, but is presented clearly and concisely.

- “It gives different insulin types, what they’re used for. So if you’re not really working out with what you’re on you can talk to your doctor “Well, I read about this kind, would this work any better, is it just the same, stuff like that.”
- “Probably make it a little bit easier to understand.”
- “It has a lot more information and it breaks down things a lot more.”

**Organizers**

Participants considered organizers important, because they would be using the material to find specific information.

- 3 of 4 participants looked at the index.
- “Because say you’re feeling bad, all you have to do is go to your refrigerator, look up jello, go to your sandwich plan. It’s not something you have to read through or measure out or figure out on your own.”
- “Actually people my age are usually looking for just one certain thing at a time.”

**Visual Elements:**

As information containers:

- “I would want to take this with me, but it needs to be in a chart…just for easy reference to look at.”
- “Say there is an 8 year old – they know by this picture and this big L that what they take.”
- “Got a lot of information, like uh… a lot of graphs.”

As attention holders:

- “Makes it more interesting, to actually look through it.”
• “Something just typed like A is not something I would have read.”
• “…it just seemed to be more into the white paper thing.”

As conveying the intended audience:
• “Where’ the teenagers?”
• “Cartoons… ……. seems like more of a family book.”

**Individualized content**

Participants desired material that is personalized to their situation.

• One participant mentioned a preference for first person text (“like the paper’s talking to you).
• “…where you can draw your own stuff in. Like, a book that tells you what you need to do, it gives you information and also you can write in what you need to do or what you’ve done.”
• “…it’s a generalization, but some of these just wouldn’t apply to me.”
Discussion

This exploratory study suggests that these 17-year-olds with diabetes desire individualized information on their health care needs, especially regarding what to do in certain situations. The organization and visual appeal of diabetes documents is important to them. They want to see other teenagers reflected in the document, but hold varying opinions on whether adults should be included also.

The ideal document for these 17-year-old females, based on pooled comments, might be a somewhat glossy, high production brochure, rich in informative charts and diagrams. Specific situations they might encounter would be included, such as what to do when you go on a vacation. These situations should be well organized and indexed. These topics might include areas to be filled in by the teen and his or her medical staff (doctor, nurse, nutritionist), allowing direct suggestions individualized to the teen’s specific case. Photographs of real teenagers should be included throughout the brochure, supplemented by occasional photographs of active adults. Photograph series of teens implementing important medical procedures may be useful. Information on current developments might be included, as well as in-depth information that they might discuss with their medical staff. This information should be easily read, but should maintain an adult quality (as opposed to childlike).

Because this study is based on brief interviews with four caucasian 17-year-old females in a single clinic, generalization of this study is very limited. Future work might explore what aspects of these findings generalize to other youth populations. A methodology might be employed that allows the participants to design their ideal brochure, either from scratch or from provided components. A similar approach might be used in regards to a diabetes-related Website. Finally, this study was limited by the brief amount of time available for interviews. A project that allowed for longer or multiple sessions, and peer interaction may serve useful.
Bibliography


