Patient Perception of Family Response to the Diagnosis of Type 2 Diabetes

Sondra Bedwell, PhD, APRN, FNP-BC
Significance

- U.S. has 25.8 million individuals diagnosed with diabetes with 95% being type 2
- Cost is $174 billion annually
- AR has greater than average incidence at 212,953 or 9.6% of our population
- Applying incidence of 95% yields estimate of 202,306
Background

• Family medicine clinic in Southwest Arkansas

• Estimated 11,000 with type 2 diabetes (T2DM) in the region

• Outpatient care, community education, medical resident training

• Five physician faculty, one APRN, 23 residents

• 1700 patients diagnosed with T2DM

• One diabetic educator
Usual Care Flowchart

Presents to Clinic
Assessment and Testing

Returns to Clinic
Receives Diagnosis
Prescription for Meds & Monitor
Handouts and Instructions to Log Blood Sugars

Returns Home
Discloses Diagnosis

Returns to Clinic in 6 to 12 Weeks

CDE referral if
Blood Sugar Poorly Controlled

Routine Care if
Blood Sugar Controlled
Research Question

• What is the patient’s perception of his/her family’s response to the diagnosis of diabetes?
Specific Aims

1. Explore the patient’s perception regarding his/her family’s response to the diagnosis of diabetes.

2. Examine the patient’s reaction to his/her own perception and how it has affected the management of their disease.

3. Identify and explore individual needs for emotional and educational support.
Theoretical Framework: Social Cognitive Theory

Person
- Self-efficacy
- Self-agency
- Self-regulation

Environment
- Family
- Finances
- Provider
- Surroundings

Behavior
- Diet
- Exercise
- Medications
- Smoking Cessation
- Self-Monitoring

Figure 1. Sensitizing Framework Adapted from Bandura, 2004
Study Design

- Qualitative, interpretative phenomenology
- Sensitizing framework: Social Cognitive Theory
- Purposive sampling
- Semi-structured Interview Guide
Inclusion Criteria

• Adults 21 years or older
• Diagnosed with type 2 diabetes within 3 months to 2 years
• Family members living in the home
• Able to read, speak, write, and understand the English language
Recruitment Process

Patient Presents to Clinic for Care

Provider or Nurse Identifies Potential Patient Participants
Inquires about Potential Interest in Study
Offers "Agree to be Contacted" Form

Interested Patient Signs "Agree to be Contacted" form

Investigator Contacts by Phone and Screens for Eligibility

Inclusion Criteria Met
Appointment Made for Consent Process, HIPAA, and Interview

Inclusion Criteria Not Met
Excluded

Does Not Consent

Gives Informed Consent

Interview
Interview Process

- Investigator conducted all interviews
- Demographic form
- Audio-recording
- Semi-structured interview guide
- General broad questions
  - “What is it like being recently diagnosed with diabetes?”
  - “What does diabetes mean to you?”
- Probe questions
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed with T2DM</td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>4 (28%)</td>
</tr>
<tr>
<td>6 months - 11 months</td>
<td>5 (36%)</td>
</tr>
<tr>
<td>12 months - 24 months</td>
<td>5 (36%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>Native American</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Family Members Living in the Home</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>8 (57%)</td>
</tr>
<tr>
<td>Child/Step-child</td>
<td>11 (78%)</td>
</tr>
<tr>
<td>Parent/Sibling</td>
<td>5 (36%)</td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>less than 10,000</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>10,00 to 14,999</td>
<td>3 (21%)</td>
</tr>
<tr>
<td>15,000 to 24,999</td>
<td>2 (14%)</td>
</tr>
<tr>
<td>25,000 to 34,999 or more</td>
<td>2 (14%)</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>Medicare and Medicaid</td>
<td>2 (14%)</td>
</tr>
<tr>
<td>Private/None</td>
<td>5 (35%)</td>
</tr>
</tbody>
</table>
### Description of Analysis Process

<table>
<thead>
<tr>
<th>Unit</th>
<th>Category</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Have family counseling, let them know how important it is”</td>
<td></td>
<td>Family Counseling</td>
</tr>
<tr>
<td>“Until they start learning more about it, they don’t know how big a thing it is..”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“New diabetics need concise, understandable information”</td>
<td></td>
<td>Education</td>
</tr>
<tr>
<td>“They say, ‘Here’s this medicine, go’ and with zero, zero education”</td>
<td></td>
<td>Classes</td>
</tr>
<tr>
<td>“Get together and ask questions”</td>
<td></td>
<td>Support group</td>
</tr>
<tr>
<td>“Have a meeting, all get together and just talk”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Encourage me on my eating habits”</td>
<td></td>
<td>Follow-up on education</td>
</tr>
</tbody>
</table>
Patient Feelings about T2DM

“What is it like to be recently diagnosed?”

[---------------------------------------------------------------]
Fear                             Shock                             Sadness

“Diabetes runs on my mom’s side of the family and my mom has to take shots every day. She has suffered over the years and I’m just scared of that. She had to have surgery on her eyes and had to have the diabetic stents put in her heart – it was scary.”
## Examples of Frequencies

<table>
<thead>
<tr>
<th>Code</th>
<th>Count (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling scared</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>Feeling scolded by family</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>Feelings of Anger</td>
<td>5 (36%)</td>
</tr>
<tr>
<td>Lack of support</td>
<td>5 (36%)</td>
</tr>
<tr>
<td>Feelings of sabotage</td>
<td>3 (21%)</td>
</tr>
</tbody>
</table>
Cycle of Feelings

- Lack of knowledge
- Feeling out of control
- Lack of self-efficacy to manage chronic disease
Family Response Types

“How did your family react to the news?”

- **Supportive** - reacted appropriately and works with collaboration to help patient manage diabetes

- **Panicked** - lack of empathy, concerned how it would affect them and not the patient

- **Challenged** - unconcerned, problem can be solved by knowing, sees it as pretty normal

- **Scolding** - nagging, scolding, criticizing

- **Worried** - concerned but not helping

- **Sabotaging** - offering or preparing poor food choices or making changes difficult for patient
Patients’ Recommendations for Providers

- **Timing** – “The doctors need to not drop it in your lap and then just leave you sitting. They should give you something right there and then.”

- **Action** – “Tell us how to talk to our family members to tell ‘em about the difference in our diets, the changes that we have to make, because ... a lot of people don’t take it that serious...”

- **Tools** – “about keeping records and stuff, ... for your sugar, everybody should have those meters...”
Patients’ Recommendations for Providers Cont’d

• **Education** – “I wish they had given me a nutritionist or something, I’ve had to do this all on my own.”

• **Individualization** – “… set up a film or something for them to watch ... you know, pick up information by hearing it and everything, pick it up better, and they could get a better understanding of what’s going on with them.”
Discussion

• Lack of education affects the way that patients present the news to their family members.

• Patients who feel unsupported by their family members also lack self-efficacy.

• If the provider “glosses over” the diagnosis, the patient may also discount the seriousness of the diagnosis, leading to lag time in control and increase in complications.
Potential Results of Provider Action

- Progression of complications
- No changes made
- Not a big deal
Limitations

• Low health literacy

• Distraction of cell phones

• Communication styles

• Family configuration
Conclusions

- Increasing numbers of people with T2DM
- Numbers of uncontrolled T2DM
- Affordable Care Act
Implications for Healthcare Providers

• Focus on patients’ individual circumstances during diagnosis disclosure

• Assess and address learning styles, education needs, and family composition

• Use CDEs to assist in the busy healthcare environment.
Long-term Goals

• Develop interventions

• Test interventions

• Disseminate successful interventions


