# The Psychosocial Impact of Patient-Provider Discussion of Diabetes Complications



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### **Presenter Disclosure Information**

## Marilyn Ritholz, PhD Declared no conflict of interest

# Outline

### Background

- Perceptions of Diabetes (DM) Microvascular Complications: Mixed Methods Study
- Objectives
- Methods
- Sample
- Preliminary Results
- Conclusions

## Diabetes Complications: Development of Other Chronic Illnesses

### Diabetes

### Diabetes Complications

(Other Chronic Illnesses)

Retinopathy Kidney Disease

**Peripheral Neuropathy** 

**Autonomic Neuropathy** 

### Functional Impairments

Blindness ESRD (dialysis, transplant) Amputations

**Sexual dysfunction** 

## Glycemic Control and Diabetes Microvascular Complications

- Achieving near-normal glycemia (target A1c<7.0%) delays the onset and slows the progression of microvascular complications of diabetes, supporting intensive diabetes management.
- Insulin analogs, insulin infusion pumps, and continuous glucose monitoring (CGM) improved diabetes management and decreased risk for diabetes complications.
- However, despite improved treatments and outcomes for DM care, diabetes remains the leading cause of vision loss and end-stage renal disease in the United States.

DCCT, 1993; DCCT/EDIC,2002, Nathan et al, 2005; US Renal Data System, 2008; DCCT, 2011; CDC, National Diabetes Fact Sheet, 2011

## Psychosocial Research and DM Complications

- Depression was associated with retinopathy, nephropathy, neuropathy, sexual dysfunction, and macrovascular complications in review of studies of T1D and T2D patients\*
- Diabetic retinopathy was associated with disruption of family functioning, increased social isolation, deterioration of work prospects, and adverse emotional responses\*\*
- Diabetic neuropathy is linked with depression, anxiety, and selfmanagement of foot ulcers\*\*\*

\*DeGroot M et al, 2001; \*\*Fenwick EK et al, 2012; \*\*\*Villeikyte L. & Gonzales JS, 2014

## **Research on Patient-Provider Discussion of Diabetes Complications**

- Few studies have explored how health care providers inform patients about diabetes complications and how patients react to and cope with being informed. \*
- No studies have explored patients' recommendations for how and when providers should inform them of diabetes complications.
- Clinicians have little evidence on which to base clinical approaches to the discussion of diabetes complications.

\* Buckloh LM et al, 2008; Lochrie A et al, 2009; Wysocki T et al, 2011

## Perceptions of Diabetes Complications: Mixed Methods Study

### **Objectives:**

➤To explore diabetes patients' perceptions of and reactions to providers' discussion of microvascular diabetes complications.

>To research patients' recommendations for how and when providers discuss complications.

## **Methods**

- Mixed-method survey to explore patients' perceptions of, experiences with, and recommendations for provider communication about complications.
- English speaking Joslin Diabetes Center patients, aged 25-85, with T1D or T2D ≥2 years, no severe psychopathology or cognitive or visual impairment
- 148 patients completed "Perceptions of Diabetes Complications" survey, Diabetes Distress (Problem Areas in Diabetes-PAID), Depression, Anxiety (Brief Symptom Inventory-BSI), and demographic survey. Medical records reviewed for type of diabetes, date of diagnosis, and most recent A1C.
- Survey data managed using Research Electronic Data Capture (REDCap). Qualitative data coded and analyzed by thematic analysis

# **Preliminary Results**

## **Demographic Characteristics**

N=148 participants	Mean±SD (range)	
% Female	56	
Present Age (years)	60 ±13 (25-85 years)	
% Type 1 Diabetes	65	
Age at diagnosis (years)	32 ±17 (1-72 years)	
Diabetes duration (years)	$28 \pm 14$ (3-70 years)	
Most Recent A1c	7.6±1.1% (4.8-12.1%)	
$\% \ge$ one microvascular complication:	71	
Eye	71	
Nerve	50	
Kidney	34	

# **Survey Results**

	Diabetes Distress (PAID) Mean±SD	Depression (BSI) Mean±SD	Anxiety (BSI) Mean±SD
Patients with Complications (n=105)	23.1±21.1	49.4±10.8	48.1±10.8
Patients without Complications (n=43)	18.4±18.2	46.8±8.4	45.6±7.7

All P-Values=NS

## First Discussion of Diabetes Complications: Representative Quotations (n=139)

Participants described providers discussing:

### Clinical suggestions to avoid complications = 42% (58)

"He (Provider) stressed good control as best way to prevent/reduce complications" (68yo Female, T1D diagnosed at 35 yo, A1c 7.4%)

### > Only factual information about complications = 23% (32)

"General descriptions of most common complications- retinopathy, kidneys" (48yo Female, T1D diagnosed at 15 yo, A1c 8.3%)

## First Discussion of Diabetes Complications: Representative Quotations (n=139)

Participants described providers discussing:

### Threats about complications = 14% (19)

"I don't remember exactly but the gist was that I would lose my legs and go blind if I did not take care of myself."

(35yo Female, T1D diagnosed at 2 yo, A1c 6.8%)

### No Information Given= 7% (10)

"My internist diagnosed type 2. Did not go into potential complications."

(77 yo Male, T2D diagnosed at 59 yo, A1c 7.6%)

### Diagnosis of Diabetes Complications Representative Quotations (n=105)

#### 80% (n=84) Perceived Provider Support

Practical Specific Guidance (n=29) "....Years ago, I had bleeding in the vessels of my eyes, and I had laser treatment, <u>two times</u>. For the unawareness of hypoglycemia, testing more than 4x-changed to 8x. Very helpful." (66yo Female, T1D diagnosed at 15 yo, A1c 6.6%)

#### Comfort and Reassurance (n=21)

*"Low key approach-no "panic" in voice"* (59yo Female, T1D diagnosed at 17 yo, A1c 9.2%)

Increased Information (n=20) "Felt better after a discussion with the eye doctor and looked at photos of my eyes." (71yo Female, T2D diagnosed at 51 years old, A1c 12.1%)

### 20% (n=21) Did Not Perceive Provider Support

Lacked Information (n=11) "Doc just said you need to lose weight; not how." (62 yo Male, T2D diagnosed at 40 yo, A1c 6.5%)

#### Did Not Assess and/or Recommend Patient Social Support (n=11)

"Ask me, 'Do you need support? What would help you deal with this?" (82 yo Male, T2D diagnosed at 51 yo, A1c 7.1%)

#### Lacked Compassion (n=3)

"...He was never sympathetic to how scary it is to know that my autonomic nervous system doesn't work properly and the chest pains are normal for me if I exercise. Compassion can still go a long way towards reducing a patient's fears and stress about their 'normal' but uncomfortable symptoms"

(44yo Female, T1D diagnosed at 18 yo, A1c 8.5%)

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#### Increased Information and Awareness (n=20)

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## Emotional Responses to Diagnosis of Complications (n=104)

- Scared 48% (50)
- Felt it was a Wakeup Call 46% (48)
- Sad 32% (33)
- Angry 27% (28)
- Guilty 24% (26)
- Hopeless 14% (14)
- Blamed 10% (10)

## Behavioral Responses to Diagnosis of Complications (n=104)

- Knew I needed to adjust my DM self-care—56% (59)
- Changed my DM self-care—42% (44)
- Was not sure what to do—12% (13)
- Did nothing; felt my DM was on track—11% (11)
- Wanted to give up—9% (9)
- Unable to change my diabetes self-care 4% (4)
- Do not remember what I did (3%) (3)

### Diagnosis of Diabetes Complications: Emotional Coping Strategies (n=104)

### **Positive Emotional Coping**

- Maintain a positive attitude 67% (70)
- Try to be as independent as I can 63% (65)
- Feel capable of taking action to minimize complications 61% (63)
- Feel hopeful about the future 47% (49)
- Feel okay about myself 44% (46)

### **Negative Emotional Coping**

- Blame myself 19% (20)
- Feel guilty 17% (18)
- Feel worse about myself 15% (16)
- Feel hopeless about the future 14% (14)
- Isolate myself more 7% (7)

## Patients' Preference For Timing of Providers' Discussion of Complications (n=143)



Early On/At Diabetes Diagnosis

Age & Individual Considerations

At Complications Diagnosis

No Response

### **Recommendations for Patient-Provider Discussion of Diabetes Complications (n=141)**

Improve Manner of Communication (65%)

#### **Be Honest and Positive**

"Be straight-forward, comprehensive, objective. <u>Don't</u> use platitudes like 'if you follow an insulin or medicine regimen, along with proper diet and exercise, you can live a normal, long life.' Don't be simplistic." (74yo Female, T1D diagnosed at 35 yo, A1c 4.8%)

#### **Know Your Patients**

"Know your patient and how much information they can handle, in terms of depth and complexity. Some need simple and others more technical info, but they all need info. It's a conversation with both parties talking, not one talking 'at' the other. Don't give up!" (49yo Female, T1D diagnosed at 28 yo)

#### **Avoid Blame and Fear**

"Don't make the patient feel guilty . Don't blame the patient." (43yo Female, T1D diagnosed at 21 yo, A1c 7.8%) Improve Treatment Content of Communication (50%)

#### Give Practical Specific Guidance

"Compassion for what is happening to the person physically combined with forceful positive and explicit guidance for staying healthy. Tell the person when and how to check blood sugar and how to medicate. Tell the person what exercise to do and when. And what foods to eat or not. Not all of it will stick, but the hope is some will and frankly, if you've got a patient in the office that's half the battle. The patient wants the help. The continued, positive, no nonsense support will make a difference." (46 yo Male, T1D diagnosed at 27 yo, A1c 8.8%)

### Improve Emotional Content Of Communication (40%)

### Provide Hope and Reassurance

"Empathize/sympathize with the patient. Recommend therapy, if possible, and help patients feel hopeful and positive about their ability to lead a fulfilling life even with complications."

(64yo Male, T2D diagnosed at 39 yo, A1c 7.9%)

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## Conclusions

Our preliminary findings suggest:

 Participants want to learn about diabetes complications and apply preventative strategies as early as possible in the course of diabetes.

 Participants value providers' positive, honest, and nonblaming discussion of complications and their use of practical specific treatment approaches to enhance patients' motivation and hope for living with diabetes

## **Conclusions (Continued)**

 Providers need to recognize, acknowledge and address patients' full range of emotional and behavioral responses to the challenges of diabetes complications.

 Finally, a longitudinal study of patient-provider discussion of diabetes complications for both type 1 and type 2 diabetes patients is needed to improve patients' ability to more positively manage these complications.

## **My Sincere Thanks**

To the Patients who shared their perceptions about and experiences with diabetes and complications.

To my Colleagues at the Joslin Diabetes Center who provided support and assistance for this talk

# **Thank You**

# **Questions?**

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