Barriers to Diabetes Self-Management Education

NORTH CAROLINA DIABETES ADVISORY COUNCIL

FEBRUARY 5, 2016

Overview of Today's Presentation

Background

Methods

Results
- Demographic survey
- Qualitative data – a theory of barriers to DSME attendance comprised of individual, system, and program factors and their interactions

Summary of Barriers

Opportunities for Improvement

Background

Sponsored project by DHHS Division of Public Health

Study Purpose

- Identify key barriers to DSME participation
- Identify potential actions/messages public health professionals and their partners can initiate or disseminate to improve DSME participation

Focus group facilitators' presentation of insights and experiences

- June 2015

Today's presentation of analysis of qualitative data

Methods

Process
- Facilitators
- Focus groups participants
- Demographic survey
- Standardized interview guide
- Audio-recorded
- Transcribed

Participant (n=72) demographics
- State Health Plan (48%), Medicare (24%), Medicaid (18%)
- Female (86%)
- Employed (>50%)
- Type 2 Diabetes (91%)
- African American (65%)

Study sites
- Wilson, Robeson, Halifax, Guilford, Jackson

Analysis
- Qualitative content analysis; 2 coders
- Standardized codebook and iterative inductive and deductive coding; grounded and latent (inferred) codes

Results

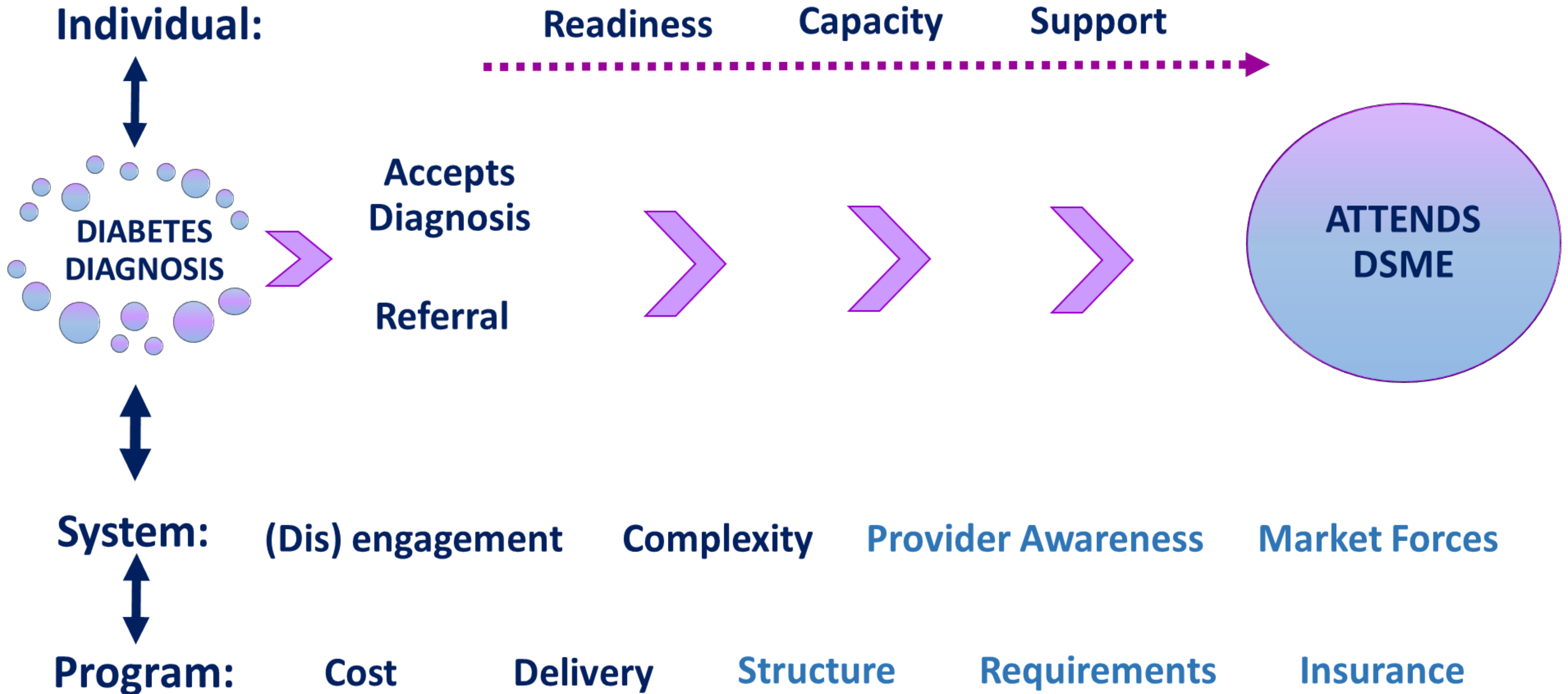
Themes

Individual-level factors

System-level factors

Program factors

Barriers to DSME Attendance



Individual-level factors influencing attendance at DSME

Readiness to modify lifestyle / adapt to condition
- Emotional readiness
- Self-efficacy/locus of control/empowerment learned resourcefulness
- Disease severity

Support
- Peer / family
- Physician

Capacity
- Awareness/education/literacy
- Resources –insurance, finances, transportation

Emotional readiness

Denial, Anger, Self-blame, Depression

“When I first was diagnosed I was angry, and I was somewhat emotional and in denial for a long time. I just was not gonna’ accept it. That was hard for me… both my parents, in their later years, were diagnosed as diabetics, but I was a little angry and in denial.” [SHP]

“When I was diagnosed with diabetes I couldn't accept it … I could not accept it because I saw what it did to my family members ... loosing limbs because of diabetes. So this is why I couldn't accept it ...” [MCD]

Emotional readiness as a process…

"It can be overwhelming when you're first told you're diabetic. And then your doctor says, here's 18 pages of things that you're gonna need to start doing….and you're like where do I begin…and for me, when I first became a diabetic, I don't think it was even until the past 5 years I even became comfortable…and I've been a diabetic over 15 years…

…

And I got to a point one day where I said…I'm not gonna' let diabetes run my life…I'm gonna' run my diabetes <u>and</u> my life. And then…all of a sudden a light bulb comes on and you're just so aware of everything and it just comes together. But you have to be at a point mentally where you get to that." [MCD]

Self-efficacy

"I never had anyone break [diabetes] down… just generalized statements, "…follow ADA 1800 calorie diet" - well show me what one looks like, in a way I can understand… I have 'this much' patience for doctors, I am sick of them…no one tells you how to manage your diet with insulin … you have to be self-educated" [MCD]

Self-efficacy / disease severity

"It's manageable if you want it to be. I found out two years ago that my blood sugar was 614, and I had gotten up to 700. But it is manageable. Within the first three months, I lost 40 pounds. I got my weight down. And god is awesome. I got my A1C back to 5.6. So if you want to do it, you can do it. A lot of times we make excuses. We say we are too tired, we don't have this, and we don't have that. But we make time to do other things. We have to understand this is our health. There are resources out there that can help you, you just have to want to go out there and get the help." [MCD]

Self-efficacy as a process

"The information that you get online and off the Internet helps to grow your knowledge base, but you just have to be hungry for the knowledge, and information that you feel comfortable with and then keep pursuing more that helps you to continue growing your knowledge and I'm into the third year now, goin' into the fourth year…each year gets a little easier and my understanding and my awareness and seeing what is actually working for me, it comes out a little more…" [SHP]

Peer/Family Support

“You know…and it takes time but I’ll tell you the biggest thing is that without support from other people….and I didn’t have that…it was a lot more difficult. And now that I have more people that I met who are diabetic…it’s easy because I can look at that person and go “I’ve had one of those days” and Marcel…she’ll look at me and she’ll go, “I know what you mean, It’s gonna be okay…take a deep breath”…and I mean…[to friend] you don’t even know this but you have been such an encouragement to me since I’ve been here. But it does make a difference that…that you just have one other person that really does know what you’ve been through. [MCD]

Peer/Family Support

"I don't know anyone who has it…just one guy who worked at the same school as me and all I remember is that he came in and didn't have feet one day… and I'm terrified, but not enough to do anything about it which also bothers me…I don't know if it's because I don't have the support or I don't even know what to do other than not eating carbs so having friends to talk to would be great." [SHP]

Physician support

"Challenge is to make the connection so that they [diabetics] know the resources that are available to them … [need to] find another way to connect…relationship with their doctor, hopefully…resources from the doctor, encouragement from the doctor…have some personal follow up…"

I think it would be better to hear it from the doctor than to see a flyer, cuz I've seen many flyers in my doctor's office, that don't mean that I wanted to go. But if you tell me to, you need to go, I might go. But if I look up there and see, but if he say you need to go, then I might be more likely to go. [MCD]

Physician support

"Usually the doctor… could basically give you up to date progress information to let you know that it's successful [DSME program], because this patient or that patient has gone for some amount of time and it's been helpful to them, and these are the feedbacks that they'd given him, because he's sort of the exchange person, and he sees whether they're successful or not, you know." [SHP]

Physician support

"Some folks don't believe they're diabetic…if they don't take insulin. I tell them it's comin'. With a doctor's recommendation most people would go…" [MCD]

"The challenge is to make the connection, so [diabetic patients] know the resources that are available to them. The relationship with their doctor hopefully… resources from the doctor… encouragement from the doctor…have some personal follow up…" [SHP]

Awareness/Education/Literacy

"A lot of times you don't know how to manage it, you don't have the knowledge on it, and a lot of times… you don't have the insurance, where you get help and stuff so, even though it's manageable, how do I manage it? Without the knowledge and the help that, like this discussion it was good and then…but other than that, how can somebody with no income and no insurance know how to get the help from." [MCD]

"There is no company or group or organization that help the diabetes people, help the people who don't have no insurance they don't have no idea...kind of control their diabetes, they need help, there's no something like that?" [MCD]

Resources

A lot of people don't drive so transportation [is a problem] [MCD]

If we was not drivin, as long as it's on a bus line I know you'll be able to get there [DSME]. Somewhere not too far like the main areas of like wherever you live, like a downtown, people can get to downtown easily or like the libraries, a lot of people can get to, and walk and live close to the libraries, so you can walk to the library…the health department…you know, you can get to the health department by the bus line [MCD]

Resources

"I think the low income, sometimes they can't control the diabetes cuz they don't have…I'm so sorry to say but they don't have the large money to pay for the expensive food…Or the knowledge…or the knowledge." [MCD]

"Like a lot of times diabetes is mainly in like low income so salads are 7 dollars a burger's a dollar, what can you afford….you gonna get that burger." [MCD]

"There's probably a lot of people that has [diabetes] don't have the money to pay for [DSME]…" [SHP]

System-level factors influencing attendance at DSME

Patient-Provider Dis-engagement

- Referral
- Communication

Complexity

- System
- Diabetes Prevention and Control Programs : DSME, DPP, MNT, Stanford DSMP, nutrition counseling, health coaches

Provider Awareness

- DSME - MNT="coaching" - dietician

Market Forces

- Health coaches

System-level factors influencing attendance at DSME: Patient-Provider Dis-engagement

Referral

"I would definitely want to go [to DSME], I was diagnosed about a year or so ago - I asked the nurse to take my blood sugar, they called and said 'you are pre-diabetic' just stop eating carbs, BYE! and that was all I got, everything else has been googling …now I am diabetic but I have not received any knowledge from anyone about anything but I'd be very interested in something like." [DSME] [SHP]

Referral

"The hospital should offer [DSME], cuz I know a lot of people go in and they find out that they have diabetes, you know, and the hospital just give you a paper, and they give you a list on the back of where you can call. but a lot of places you need insurance, but it's no discussion, I know they got the mental health on there, they got all this stuff on the back where you can call a hotline but it's nothing about diabetes or nothin', maybe if they had a hotline number where maybe people you could call, and they'll tell you where those types of things is." [MCD]

Referral

“Maybe it would make a difference if a doctor tell you [to go to DSME], because then you’ll know more about it…So if your doctor said, oh it’s a class about diabetes … you’re probably more likely to go.” [MCD]

Communication

"When I was first diagnosed I went to the class at the hospital… I've never went back because it was basically everybody in the class had diabetes, it was a nurse, that did the class, and you know, she just went over diabetes in general, and answered people's questions, which really kinda made me have more questions because, my doctor said after a meal, they didn't want my blood sugar over 120. Well I go to this class and I'm sittin' there listenin' to this nurse tell us that your sugar could be 180 and below after a meal, so you know, how much sugar? What's your cutoff point as a diabetic? Where do you stop, you know? How much sugar can I have?" [MCD]

Communication

"You need to communicate effectively with the doctor… You need to take control of your diabetes… You have to say, doctor what should we do next? You can't be passive. There's 1000 patients and 1 doctor." [MCD]

"When my doctor told me, when I first was diagnosed, my doctor told me about, it wasn't a class but she sent me to a dietician, well that, either I was in denial or somethin' but that did me absolutely no good and I kept thinkin, my mother is a diabetic, and she was diagnosed maybe the year before, and I kept thinkin, if I didn't have the initiative to go out and search information myself, what she'd said to me wouldn't have helped me at all." [SHP]

System Complexity

In any community, which agencies are referring?

- What are they referring for?
- Who is eligible?
- What is covered?
- Does how/does follow-up occur?
  - Between providers?
  - Between MD and patient?

Program Complexity

- Diabetes prevention and control programs: DSME, DPP, MNT, Stanford DSMP, nutrition counseling, dieticians, health coaches
  - E.g. referrals from large internal medicine practice to local health department
  - Referrals are often made for MNT only
  - Certified diabetes educator follows-up with practice – don't you also want a referral for DSME?
    - Difficult to reconnect…

Program Complexity

- Suggests provider lack of awareness regarding services and their availability…
- True also for patients…
  - “When I was first diagnosed, they sent me to some nutritionist and they showed me how to use the meter and they gave me…and then they gave us a meter and showed us how to use it and all, and I don’t know who paid for that, I don’t remember payin’ for it but, I think we had to go a couple of times to this class and after that it was over so I feel like I need a refresher, I’m probably doin’ all the wrong stuff…” [SHP]

Market Forces

What competition exists in the local public health system?

- E.g. reduced referrals to LHD DSME program when large local private practice group institutes "health coaches" to provide diabetes education
  - 1 session
  - billable

Program factors influencing attendance at DSME

Cost

Delivery

Structure

Requirements

Insurance

Cost

"I don't know but I know if there was a cost that would be convenient for me and it's important enough for me, I would pay. And if the information was valuable …what kind of information are you presenting to me, what am I paying for? If it's worth my time and worth me, getting something out of it and it's benefiting me yes, I don't mind paying for it, but…" [SHP]

"…if there were a series with copay id be willing to pay it…" [MCD]

Cost

"There's probably a lot of people that has [diabetes] don't have the money to pay for something… Not necessarily they don't want to but they don't have the money to…sometimes when you start buying the food its gets expensive. And your meds are high too….it can add up…" [SHP]

"It should be according to your income - based on your insurance…" [MCD]

"I wouldn't make it pricey…" [MCD]

"It would have to be free…" [MCD]

Location

“Well the health department is in a good spot…it’s not too far from everywhere - they have a bus line. Libraries. Maybe Social Services …the bus line is right there.” [MCD]

“Hire a diabetic educator and give them one of these cars and have one meeting per month until your populations are reached…talk to the churches and use their facilities…tell them you're having a diabetes class and they’ll come, too many people don’t know anything about it.” [MCD]

Location

"Or even if they hold the class at the doctor's office, a room at the doctor's office, and that counts as one of your visits, you just pay a co-pay." [MCD]

"I think the hospital, really…The hospital probably the best. [SHP]

"Get involved with the local churches…" [SHP]

Time

“Early evening would work…you know say 5:30 – 6:00, something like that where you’re day is at the end, giving you a little lapse between that and work so…” [SHP]

“Saturday would probably be the best for me…” [SHP]

“For me, I don’t like giving up my weekends, weekdays work better for me, early evenings is good…” [SHP]

Method

“**Online** is good yeah…Most of us we have our Internet or we have our phone; our phones are covered by Internet. You can see the messages. It’s easy to see them in phone…” [MCD]

“I think it’s **[online]** a great idea; a lot of times…everything’s online, you watch Netflix on your TV and if there’s a discussion class and the information that’s online it’d be a lot easier for a lot of people to access it that can’t get out the house, that may have access to internet at home, especially with these smartphones you can watch it right on your phone…[MCD]

“I think both would work, **webcasts** … cuz with the webcast you can type in your question while everybody else is talkin’ and then they get your question and then they answer and stuff so, those us that’s computer savvy, to me it would work great.” [SHP]

“I’m not going to sit all day” [MCD]

“More than a couple hours for a session and you probably won’t get them to come back” [MCD]

Program factors influencing attendance at DSME

Insurance

Out of state insurers?

BCBS co-pay?

BCBS deductible?

Medicaid?

Reimbursement tied to ADA program guidelines

Structure

12 months from date of referral to complete the series, followed by 2 hours training in subsequent years

- Readiness
- Great variability in NEED for program, e.g. new diagnosis, versus old, comorbidities

Requirements

Required program teams limits availability

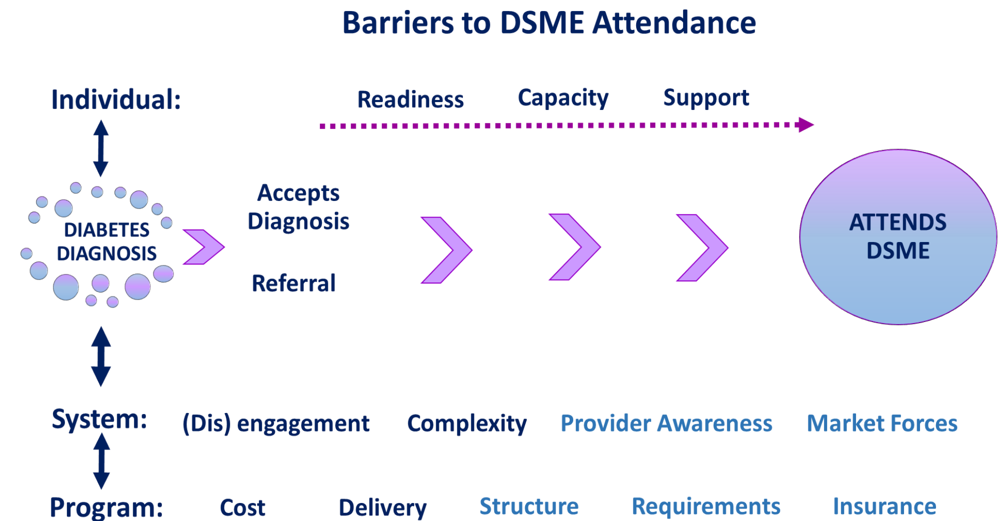
(In) Flexibility

- Market segmentation, e.g. on-line, face-to-face

Summary: Barriers

1. Accepts Diagnosis (varies over course of illness)
2. Referrals **Readiness** ⟷ **Referral**
3. (Dis) engagement
3. Complexity
4. Cost
5. Delivery (static - tied to guidelines)

Readiness ⟷ **Reimbursement**

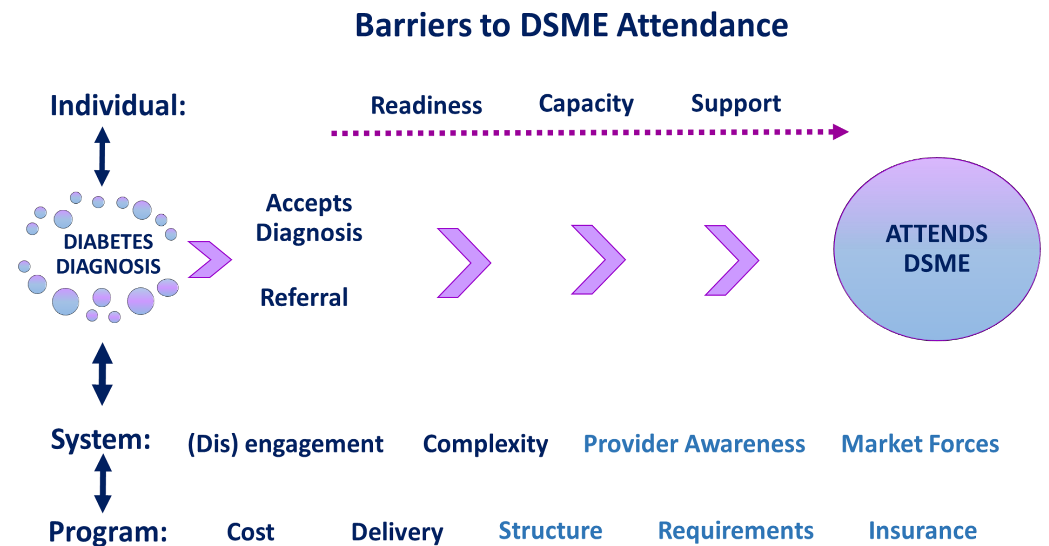


Summary: Opportunities

Intense Engagement

1. Accepts Diagnosis
   - Motivational interviewing; Physician follow-up/support; empowerment
2. (Dis) engagement – physicians/teams/offices are central
3. Referrals
   - Outreach
4. Complexity
   - Program branding
4. Cost
   - ?????
5. Delivery – flexibility
   - Setting
   - Time
   - Tie to patient need - dynamic

Clarity



Recommendations for future research

Focus has historically been with the patient, with less attention to system barriers

- Examine system perspective (e.g. referral patterns; competing programs, e.g. “health coaches” in Edgecombe, “other” education in FQHCs and HDs)
- Examine payer perspective
- Examine program delivery (e.g. fidelity, capacity)

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