

Connecticut Medicare & Medicaid Eligible Demonstration: Participant Focus Groups

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Julie Robison, Noreen Shugrue, Pamela Higgins, & Kelly Ruiz

Project Goal

Evaluate the health care experience of persons age 65+ in Connecticut who are eligible for both Medicare and Medicaid (MME) benefits

- Use a consistent, person-centered, and culturally-sensitive method
- Inform the design of the integrated health and social service demonstration program for CT MMEs

Procedure

Focus Groups sample was recruited in collaboration with members of the Complex Care Committee of the Medical Assistance Programs Oversight Council, the Money Follows the Person Steering Committee, and community-based organizations:

1. Identified focus group participants
2. Invited them to participate in a session
3. Managed refreshments, gift cards, transportation

Procedure

- Center on Aging provided the community-based organizations with a letter and flyer for recruitment purposes and contacted each volunteer to confirm eligibility status and explain the focus group.
- Organizations involved included access agencies, AAAs, community health center, nursing home groups
- Covered all 5 areas of the state: Eastern (2), North Central (1), South Central (2), Southwest (2), Western (1)

Sample

Description of Population	Number of focus groups	Number of individuals (65+)
Nursing home residents	1	11
Community dwelling individuals (healthy and chronic disease or disability)*	5	42
Spanish speakers	1	10
Family members of individuals with chronic disease or disability	1	8
TOTAL	8	71

*Well and frail individuals mixed in each group. One group contained several individuals who worked as companions for others

Analysis

- Each focus group facilitated by 2 researchers from UCHC.
- Four researchers with varied backgrounds (public health, gerontology, psychology, law, finance)
- All focus groups recorded and transcribed word-for-word
- Data coded and analyzed by research team

Analysis

- Code list established through use of focus group guide, and expanded in iterative process
- Recurrent themes noted and text clustered under each theme using constant comparative method
- Disagreements resolved through discussion, consensus building and code refinement

Findings

Focus Group Questions Domains

- Current Experience
- Care Coordination
- Consumer Protection
- Ideal Health Care & Service Program

Current Experience: Doctors

1. Please start by describing what happens when you need to go to the doctor or clinic. Do you have one main doctor, or more than one? How many doctors do you see?
 - a. Is it easy to speak with someone or ask questions without going to see them?
 - b. What types of doctors or other health providers do you see?
 - c. What do you do when you are sick and you can't reach your doctor or his/her office is closed?

Current Experience with Doctors

Themes

- Most common arrangement: 1 PCP in a primary care office, consistent over time, with 1-4 specialists in different practices and locations
- Most see the same docs, though some get switched around to a rotating group of newer/younger docs
- Those in hospital-based clinics see rotating docs
- People often, but not always, see site-based doctors in congregate housing (if available) and nursing homes

What doctors do you see?

So I don't know how many doctors. What I do is tell the nurse, "this is what I'd like to have checked, you take care of everything." I don't ask when, how, or what. I know that I'm in good hands.... And I just sit on the sidelines waiting to hear what's going on

My main doctor is here at the clinic. He's my primary care doctor, but I also have a kidney specialist at Yale, and I also have an eye specialist. My primary care doctor...will call in another doctor and they will discuss my problem and will, together, come up with the solution... I feel that this service is very good.

Whoever comes, I don't know. Some of them I don't know their names! [NH resident]

Current Experience with Doctors Themes (Cont'd)

- Most don't have issues calling/reaching docs; some complain that calls are screened or staff does not pass on messages.
- Many have issues with distance and transportation
- If doctor not available, most would choose ER
- Other options include family, RSC, care manger, 24-hour clinic
- **Where alternatives to ER exist, people willing to use them**

Is it easy to speak with someone?

My dad's doctor is very approachable. If he is available, he gets on the phone. If not, he calls back and he'll spend 45 minutes on the phone. He is good always [family member]

Most of the time, I can call and I can talk to the head nurse.

I have to wait to get in here to see a doctor before I can find out anything because you can't get them on the phone, you can't get anybody to answer your question.

No, you can't, it's all recording and I am not going to deal with that...Unless I can talk to a person I won't talk to it, I'll drive there first

What if you can't reach your doctor?

If he's not available, there is always some other doctor ...there that will answer his calls. And they will either tell me that they can see me at the office – or go to the hospital and they will see me there

When I am sick and I can't reach my doctor because it's late at night or it's closed ...I call 911 and they send the ambulance and they take me to the emergency room

I call the on-call person and they are very good too. They call back even if it is 11 o'clock at night, and then I explain the situation to them and then get their opinion [family member]

Current Experience: Transitions

2. If you stayed in the hospital or a nursing home in the past year, what did your health providers do to help you prepare to go home? Did you understand their instructions for taking medications and seeing your doctor after you left? What other help could you have used?

Transitions Themes

- Many described positive transitions
 - obtaining needed services/therapy at nursing home or home
 - receiving instructions from the doctor/hospital/nursing home
 - residents of housing who used an affiliated nursing home were guaranteed to keep their apartments
- Some did not receive enough services at home after transition
- Transition problems were more common between nursing home and home

Positive transitions: Receiving needed services

I had a nurse three times a week. A woman who came in and bathed me every day. A woman who came in and cleaned my house—did laundry, ironing, cooking. I had a lot of services, and it was good! And everything was paid for! I had the maximum hours with my health.

The nurses discharged me [from the hospital] and told me the medication I was supposed to take, what time I was going to see my primary care doctor, he came by to see me, and yes they prepared me, I think they did a nice job, I think so, I don't think I was neglected.

As a matter a fact, I had an appointment to see my doctor while I was in rehab. They took me by ambulance because I use the doctor here. And then they set up another appointment for when I returned home.

Positive transitions due to receiving instructions

They gave me a list of my medications and informed me about what I was taking and what I should be on.

They prepared me, the nurses came and they discharged me told me the medication I was supposed to take, what time I was going to see my primary care doctor, he came by and see me, and yes they prepare me, I think they did a nice job.

They told me to watch how I walk because I have rods in my leg, that's why I had to go to rehabilitation to learn how to walk all over again. I was still on the same medication. My doctor...he said to send me to a therapist. And I asked him if I could come here, because I know M, I had experience with him, and he said yes.

Medication issues after nursing home discharge

*It was a mess. It was piles and piles and stacks of cardboard medicines and sticky notes – and I'm like "what the heck is this."
[family member]*

She's a diabetic, they sent her home with no insulin at all, the medicine was a mess, from the nursing home to home. And it was just the first couple of weeks, and she's been with us since October, and she has been in the hospital two or three times already. [family member]

Current Experience: Prescription Medication

3. Please describe what happens when your doctor prescribes a medication, what does he/she tell you about the medicine? (Probe: purpose of medicine, how to take it, possible side effects or interactions with other medications, when/who to call about problems with the medication)

Prescription Medication Themes

- Most doctors explain the basics such as dosage and when to take medications
- The majority of people rely on pharmacists for any medication questions
- Some people rely on written instructions
- Many said visiting nurses help with education; medication organizers are also helpful
- Some described communication problems leading to confusion about their medications
- A few had interpretation issues due to language barriers

Most doctors explain the basics

Well he tells me when he's giving it to me. Then he asked me the other day, Do you take – I can't even remember the name of the medicine – it's a heart medicine. He asked me do you still take it?

Some of my medications that I get that are prescribed, they explain the side effects – they check to see if [the new] medications that I am taking will react to the medications that I am already taking. They're very good.

The outside doctors, yes they do. They explain everything to you. They tell you what the medication is and what it's going to do and what it's for. But the doctors in here [NH] do not. Except for a couple of them. I have to say, there are a couple. [NH resident]

Majority rely on pharmacists

I'm on a lot of medication and... the pharmacist is fantastic, there was one medication I was put on and he said: "you can't go on that while having the potassium, have the doctor stop the potassium" and he put me on this other heart medication, and there is a paper that comes with it but the pharmacist is very good, very good.

But when you are given prescriptions, and you don't know when you have to take this one, and what is this other one for, that is why the pharmacist tells you: "if you don't understand the instructions ask us and we will answer you."

What I do if I have any questions about the medication is to go to the pharmacy or give them a call and they are very thorough and if there are further questions then I check with the doctor

Communication problems leading to medication confusion

*They [doctor] might only see them once a month, every three months, every 6 months, but I know that person, I live with that person. .. And at one point, my aunt she had very, very high levels of potassium which would have killed her.
[family member]*

*Her Coumadin levels were way too high... it was, “you know your mother’s Coumadin levels are at a dangerous level.” At first they were trying to blame it on me. “Wait a minute, you guys are giving me medication, and give her this and this and this.” And I’m going by your instructions and now you are blaming me because the Coumadin levels are too high. That was crazy. Really, that was too much. But it really is important that they communicate.
[family member]*

No, they don’t give me instructions because it has happened to me that I wonder “what is this for? What is this other one for?” and no, no, no, they are not willing to give the patient their attention to explain in detail what is this for and what is that for.

Care Coordination: Communication between Doctors

4. Do you think your doctors talk to each other about your care? Do they work together? How do you feel about the idea of your doctors talking with each other and with other people who help you to figure out what you need to get healthy or stay healthy?
 - a. How should you be included?

Communication between Doctors Themes

Most participants think their doctors do communicate with each other, though many are uncertain

- Most think this communication takes place via FAX and it mostly concerns their prescriptions
- Some think their physicians are able to share information by accessing the patient's electronic medical records

Communication between doctors

Most of the doctors will FAX each other that is the way they do it now, they don't actually talk to each other they fax the information

It's just that I'm sure they have to talk to each other. I have a couple doctors, maybe three doctors, they have to confirm

My problem my nephrology doctor knows already who is my oncology doctor and I think they are not talking to each other because he said: "we need to meet because I don't think you need what he is proposing right now" that is what he told me, but I don't know if they had meetings

They call each other, they all have the medication, they can pull it up, same with results from CAT scans and MRIs, everything – they all have their computer systems where they can – and I allow them all (you have to allow) basically sign the authorization to allow them all to talk to each other about pretty much everything and anything from within

Communication between doctors

Prior to my father moving in with me and my husband, his three main doctors did not speak to each other...when he was in the hospital, I was my father's POA, I requested in the hospital that all three of those doctors get together with me in one room and we did. And it was the first time ever – and they have all been his doctors for 25 years. And since that moment, they have now for a year and a half, been completely in touch with each other and it has made a huge difference.

[Family member]

I just don't know; I have never had any indication that they do, I just couldn't tell you.

I don't think they do

I don't know...if the case is serious they communicate with each other

Communication between Doctors Themes (Cont'd)

- Most participants think communication between physicians and other healthcare providers is very important
- Most do not see the need to be involved in these conversations but think it is important for a relative to be involved
- Most participants do not think their doctors communicate with the homecare providers unless this person is a visiting nurse, in which case, the participants think the nurse updates the physicians on their conditions.



Communication between doctors

I think it's a good idea – if one is giving you one medication – and the other one gives you something that disagrees with that – I think it's good that they communicate so that they will know –

It's like police departments in different states in different parts of the country. They need to communicate with one another if they are going to do anything substantial. And I think that the same thing holds true for the medical profession.

Communication between doctors and family members

I'm happy, I had the same doctor for 30 years I got him just after he came out from college and I will not change because he does everything for me so much that sometimes he thinks I am not following his orders he calls my daughter

My daughter has Power of Attorney also. But I take care of everything myself. They will call her and tell her if I'm ill and tell her what the problem is, but they also tell me and they tell me what they're going to do and so forth along with telling my daughter.

Well, my daughter's my Power of Attorney. And she comes wherever I'm at. And they tell her what's going on. Even the nurse here, before they sent me to the hospital, they called her and said "your mother's doing this ahh we're sending her to Midstate." So I think your Power of Attorney is very important at this point

Care Coordination:

Having a written care plan

5. Have you seen a written plan for your care? (Probe for examples or details, who contributed to the plan.) If not, would you like to have a written care plan that includes details about all the medical care and other services you receive?
 - a. How should you be involved in the team who puts the care plan together?
 - b. Who else would you want to have input into your care plan? (Probe for family.)

Care Plan Themes

- There was some confusion as to what a care plan is; participants reported seeing documents about:
 - Homecare
 - Medications, i.e., medication schedule
 - Medical records
- Opinions on who should be involved in designing a written plan varied from not wanting anyone else involved to wanting at least one relative involved
- Caregivers reported that they want to be involved in their relatives' medical plan and the elder should be involved if she/he chooses

Care plan

Yes, it's called a care plan, it's at my door, it's from [agency] and it's a yellow piece of paper and when the nurse aides are going to be out or someone takes her place they read the care plan of what is expected of her to do

It's mostly about the home, but with the nurse coming – the nurse actually comes from the homecare facility – and so what she does is that she stays in direct contact with my mother's primary care physician – so that everything works well.
[Family member]

Yes, I have [seen a written care plan at the nurses' station] they've got your daily routine and your personal things—what you like, what you don't like.
[NH resident]

I have one for high cholesterol and it has the meals for breakfast, lunch, and what foods to buy to keep healthy, but my doctors rely on me to tell them who I've seen and what the outcome was

Yes, I have one taped in my refrigerator to be opened at my demise

Care plan

When I go to the doctor they give me a written plan, if I go to the cardiologist he also gives me a written plan, and if I go to another doctor I also get a written plan

They don't give it to me because I don't have a nurse who comes to my home or things like that, they never give me one.

I have everything on the door of my fridge, for example, I have the name of my doctors, who do I have to call, if I have to call Mrs. X I have her number there, if I have to call Dr. X I have his number too; I mean everything is in there...they have given it to me, when I had surgery Mrs. X. went to my house and gave me her phone number in case I needed something, she told me what to press for Spanish and to leave a message for her and all of that and I have that one the door of my fridge at home

Well, they give it to you so you can follow it, so you show it to the nurse who comes to check on you and she goes over it and explains it to you better.

Who should be involved?

I don't think is necessary for anyone to be included except for the doctor or myself, well, I have a power of attorney, so it'll be up to those two, whatever happens to me they have to tell him, I have a will and a power of attorney so whatever happens they would to discuss that between them

Well there's quarterly meetings with your doctors and your physical therapists, your family members, anybody else who was with your health care. And everything is taken up at that meeting [NH resident]

I don't know – we're not medically trained. You have to trust in believing in your doctors. You have to have a lot of faith in your doctor. If you don't have the faith that he is going to help you and do what is best for you, then why are you even bothering to go to him in the first place?. You have to leave it in his hands. As far I say, I'm nosy, so I'm looking over at his notes, but the thing of it is that I still have faith in him that he's doing what is best for me.

Care Coordination: Day-to Day Help

6. Who do you rely on most for any help you need from day to day? Include both unpaid and paid help. (Probe for community participants: do you have any paid helpers in your home? Do you go to an adult day program?)
 - a. How did you find these helpers/programs? Did your doctor help you find them?
 - b. Would you be interested in working with an expert outside your doctor's office to find services?
 - c. Do your doctors talk to the other people who help you, for example a care manager or home health nurse?

Day-to Day Help Themes

- Most rely on family, care managers, resident service coordinators (RSCs) to find help that includes VN, companion, ADL/IADL help and housekeeping
- Some rely only on themselves; want to maintain independence as long as possible
- Persons on CHCPE had more help at home, including LTSS, transportation, medical issues, emergency services

Who helps you get services?

“We do for ourselves. We want to do for ourselves as long as we can”

“A friend of mine set it up for me”

“My visiting nurse set it up”

“The social worker [RSC] does it”

“My case manager gets me the things”

“My daughter, she finds out”

“A coordinator at the building I am at”

Day-to Day Help Themes (cont'd)

- Very few said docs ask about help at home
- Communication between doctor and visiting nurse common, but not other helpers
- Some not allowed their choice of providers when no contract with access agency
- **“Gatekeepers” (family, RSCs, care managers) can be both helpers and obstacles**

Two roles of “gatekeepers”

But to tell you the truth I wish they wouldn't [tell my children] because they drive me crazy. It's like, if he says take it easy, they don't want me to move. You know what I mean. To me take it easy means move a little slower or take a rest when I'm tired, it doesn't mean laying completely inactive. They are like, don't get up. I'm getting some water – I'll get it for you. I don't want that. I don't want to be treated like an invalid.

When you need something you refer it to [RSC] and she does it, and she contacts my meals on wheels worker and they work together ... I had a problem when I first began and my problem was my home health aide did not come when she was supposed to come... And when I had that problem I told [RSC] and there is no misunderstanding ... it also pressures them to do what they have to do to see that I am not alone, we have somebody to look about us.

Do doctors talk to people who help you?

The nurse that comes to see my mother is from the agency so she is always talking to the doctor for medication issues [family member]

I never found an instance where a care manager or anyone needed to talk to my father's doctors [family member]

They second guess the doctors, that is the whole thing with these nurses

No, I doubt it; they probably don't even know that there is somebody

Care Coordination: Seeking emotional care

7. If you wanted to see a doctor about your emotional or mental health, for example if you were feeling sad or worried, would you know where to go or what to do? (Probe: would anything prevent you from seeking this care? Probe for finances, not knowing who to ask, stigma.)

Seeking Emotional Care Themes

- Many people have used mental health care, including treatment for substance use disorders, some for a long time
- Most people would go to their primary care doctor, social worker, or resident services coordinator for referral
- Some participants did not know who to approach for emotional care
- Some participants experienced problems accessing mental health care, e.g., physicians not taking Medicare or Medicaid
- Participants did not seem to hold stigmas about seeking emotional care, many shared their personal experiences

PCP as first resource

Yes, if I am feeling sad or depressed I call my doctor, he is supposed to give me an appointment so that I can go see him and he can determine where does he have to send me because of my depression or something that I might have; the doctor has to see you so that he can determine what it is and send you to another doctor

I would start with my primary doctor and then let them refer me

*I would ask her regular doctor...I've come to a point where I can trust him. I watched how he works. So I would definitely take a suggestion from him.
[Family member]*

Other people participants would approach

I have my own person that I see and she left her card with her number on it so that I could call her myself. She is from outside but she comes here.

I would call my nurse practitioner

I [know who to approach] because of my ex-wife, I bring to for mental health every month, right here would be the place to go; I would probably try to take a shortcut and when the nurse comes and visits her, I would ask her, and she would probably make me a referral.

I would call my son and he would find who would I have to go to or something

*I would approach the head nurse on the floor.
[NH resident]*

The social worker.

Call the doctor and [RSC]

I had anxiety – but my daughter is a psychiatrist, and she connected me with somebody.

Problems with access

I was having some psychological problems and I went to day program at [agency]. I was there a week or two weeks and it didn't help me.... They put me in the Alcohol and Drug abuse program and I have been sober for 27 years. So....I went down to [agency] and they gave me a case worker and she saw me for 2 or 3 weeks and then she passed me off to someone else. And [he] said, "oh I don't take your insurance." So then he passed me off to some other guy. I said, "you know something, we're done."

if you don't have the right insurance they're not going to talk to you. It's a shame that it has to be that way. Because a lot of people that could use that kind of stuff. You know, especially when we get up in our years.

*That is the specialist whom we cannot find because she has depression and has been on medication for many years... She was under the care of the doctor who left the group... but he does not take Title 19 anymore.... The office he left does, but they... wouldn't take his patients. So she was left...without a doctor
[Family member]*

Past experiences

The clinic here, that I use, has a psychiatrist, you just have to call and say you're feeling bad. Because I went through an issue ...and she helped me through a lot.

A while back, I OD'd and was in the hospital and they had a doctor. And so when I came here I thought since everything was here, it would be convenient – but because I left here, the mental doctor couldn't see me because my primary care doctor was no longer here. So I had to change – so now I do everything at [hospital name]

Consumer Protection: Complaints about Care & Patient Rights

8. If you have a problem with your care, would you know where to go or who to talk to, to complain? Did anyone at your doctors' offices tell you about your rights as a patient?

How to Make a Complaint Themes

- Many said they don't know how to make a complaint
- Some would talk to health care provider directly
- Others mentioned specific people they would ask for help:
 - the practice administrator or the hospital affiliated with the practice
 - family member
 - care manager/service coordinator
 - a specific community agency or 211
 - head nurse of nursing home unit/nurse manager
- Some would change doctors instead of complaining

Don't know how to complain

*NO – Just recently got involved in this – the agency that sends people, I can call and complain about the caregivers – but I don't know about doctors
[family member]*

I have a handicapped son who is mentally challenged....I know what to do for him but not for myself, I have no idea what to do if I was displeased; no I have no idea

Would talk to health care provider directly

I had a problem with my primary care doctor and I let him know, my main problem with him was if my appointment is for one o'clock I expect you to see me at one o'clock not one thirty ... why are you doing this, if you want the appointment at 1:30 say 1:30, don't say one o'clock. The person who creates the problem I get that source, my problem was with my primary care doctor so I got him ... and I talk to him about it and the problem ceased after I talked to him about it.

I would rather talk to my doctor personally and work it out including me and him if we have a problem, I don't know why I would go to somebody else

Who would you contact?

I would complain to my daughter, she knows what to do about the problem

I spoke with the medical director but since then I have been treated well

I would approach the head nurse on the floor [NH resident]

I would call AAA to tell about the problem. They handle a lot of problems

I would call my case manager.

I would call 211 and I would keep calling until they solve the problem

Change doctors instead of complaining

I would say if you don't like the doctor then you change it to another one

Doctors, you just change doctors. Get them in the pocket[book], you know.

Patient Rights Themes

- While some reported they have been told about their patient rights, many others have not
- Some people had received paperwork about patient rights or seen them posted info in provider's office; a few had read them
- Information on patient rights was not really distinguishable from privacy/HIPAA paperwork or other information supplied when services begin

Patient rights

When I came here they told my son what my rights were because I was so sick. Then he came and explained it to me.

I've never heard them talk about it but you get a sheet with patient rights

my doctor gave me a pamphlet with patient's rights so every so often I read them

Oh yeah, I read it, there is nothing else to do while you are waiting, you are sitting there and you read it over and over and over, I've already read it three times ... please, put something else up there for me to read now, why is it only in two languages, when we have twenty-something people in the waiting room in five different languages?

you know that whole HIPAA sheet is somewhere around there but it's buried.

Consumer Protection: Provider Choice

9. Do you feel that you are allowed to choose the doctors or other medical people who provide your care, or do you feel pressure to go where someone else tells you?

Provider Choice Themes

Participants reported a wide range of experiences in provider choice

- Many people have had the same doctor for many years and never wanted to change
- Some have been able to choose any doctor they want
- Patients of hospital-based or housing site-based clinics can choose within participating providers and generally find doctors they like
- Specialists were generally identified through PCP referrals with no choices, but many people trusted their PCPs to identify a good specialist



Provider choice

only had the one doctor and never wanted to change. I can speak to him like a member of the family.

If you use the clinic here, you can go downstairs and choose.

if he refers me to somebody I take his word on it because they take Medicare

I would rather be able to choose and I am able to choose.

I want a doctor, I pick myself, what I need for a particular sickness, one doctor had speeches in the evening ... I heard on the radio and marked down on paper and I made an appointment and ever since he has been my doctor

Provider Choice Themes (Cont'd)

- Nursing home residents could not choose their doctors
- Others reported lack of choice in LTSS providers, and denial of requests to change
- A *significant* number had been turned away by providers who don't accept Medicare or Medicaid, even from doctors they have seen for many years
- Several reported that they don't know how to find new doctors

Provider choice

It's hard to get a doctor these days. It's not like it used to be years ago you could change easily, but now you can't do it so easily because of ... your insurance – if you don't have the right insurance, you don't always get the doctor you want. Or many times they will tell you that their load is full.... So a lot of people hang on to their doctors knowing that he or she is better than not having a doctor at all.... they have tried to change and many are on Medicaid or Medicare and they say "no we don't take those".

Provider choice

I had a doctor tell me he is not taking Medicare anymore. So I looked at him, I was in a stupor, I mean, what do you do?... I used him for 25 years and then one day I get a letter in the mail, "Dear [name]"

no you can't change, I tried it. [NH resident]

I needed some time for myself and I needed somewhere to place her for about a week... I had to put her some place where I didn't want to because she had been there before. So I didn't have a choice about the place that I wanted her to get the care. [family member]

I'm thinking about getting another primary care doctor – I'm very dissatisfied with the one I have – I've had him for a very long time. But he just doesn't seem to have a clue.... I don't know where to start to try to find another primary care doctor.

Consumer Protection: Discrimination

10. Do you think some health care providers treat people differently because of their age, race or ethnic group, or because they receive government-funded care like Medicaid? ---- Why or why not? (Probe for examples.)

Discrimination Themes

- Most reported no problem with discrimination
- Others had experienced discrimination based on
 - Race/ethnicity
 - Age
 - Use of Medicaid (or Medicare)
- Others reported poor treatment, with no clear cause
- A few felt they receive better treatment due to their age
- Family members reported better treatment when “someone is watching”

Discrimination

I am very fortunate that all along I've had excellent medical care and I have been treated with respect and also the office staff, generally, has been very wonderful, so it's a real gift.

I don't know if it's discrimination or not, it may come under that, I missed an appointment because transportation did not pick me up on time and they said: "can you come in the afternoon?" and I said: "no, I don't have the transportation" and he made me wait three months for an appointment.

I think I am treated better...he pays a lot of attention and a lot of times I come in and the office is full and he doesn't rush me.

Discrimination: Ethnicity

I had an experience they sent me for an MRI and the interpreter, you know there are those interpreters who speak on the phone, so you know they ask a lot of questions, so I couldn't understand well and the interpreter did not treat me well, he said to me: "are you deaf?" and I said to him: "that is not ethical and you are a professional" and he said: "shut up" and I could not tell anyone because I do not speak English. But those things are abuse.

...all he did was clip my toe nails... he sent this outrageous bill to Medicare saying that he treated me for sores on my feet...for open wounds.... Because if he could get away with it he would.

We are treated differently because of discrimination ...one time I told my homemaker to serve as my interpreter because I did not trust the doctor ... When the doctor came he ordered the homemaker to go outside and so the nurse told him that she was going to be my interpreter that day, so the doctor did not see me that day, he threw the papers at my face and threw my cane to the floor and went away and did not see me.

Discrimination: Age

I was taking care of a woman who has since passed away. And I was helping her and I took her to a doctor and he kept saying, "What do you expect at her age?" and so he didn't seem to take her complaint seriously and there was something wrong with her and he kind of dismissed it because of her age.

I just went to a gynecologist and my doctor's assistant – she had a chip on her shoulder – because everybody was pregnant. They were all young, and then comes the old lady and she had to help him with me.

I can generally tell when people really don't want to know that I am there, they don't want to see me, and it's happened many times and more often than not I get the idea that being an older person, the younger people don't want to deal with you because they are certain that you are ignorant

Discrimination: Medicaid

That is the specialist whom we cannot find because she has depression and has been on medication for many years.... She was under the care of the doctor who left the group... but he does not take Title 19 anymore.... The office he left does, but they... wouldn't take his patients. So she was left...without a doctor, and everybody in case management is trying to be very helpful and giving me a lot of telephone numbers – but my mom just needs one doctor. I can't bring her to the hospital today and see one doctor and then see somebody else tomorrow. That's not going to work with her. [family member]

I have several doctors and they dropped me because of Title 19 and they were all fine doctors but I hear the reason is that is the system is so slow for them to get paid they don't like to handle Title 19

“You cannot stop watching”

I would say that healthcare workers treat people differently according to their involvement with the family.... there is a difference in the way they treat people based upon the actions and attitudes of their family members. [family member]

You have to be very on top of visiting your relative in the NH. You have to always be popping in when unexpected to see what they are doing. You cannot stop watching them. [family member]

Ideal Health Care and Service Program

11. How would you describe an ideal health care and service program for you? (Probe: co-location, team approach, your involvement in making decisions, family involvement, services provided – e.g., home care or home maker)

Ideal Health Care and Service Program Themes

Provider Health Care Services

- Most want more doctors to accept Medicaid and Medicare patients
- The majority would like to have shorter wait times to get doctor appointments
- Some described a need for their personal doctor or office nurse to be available to communicate with them when they are hospitalized
- People described a holistic approach to health care with their primary care and specialist located in one town, or in one location

Ideal Health Care and Service Program Themes (Cont'd)

Provider Health Care Services

- More coordination between medical care and home care
- Add a navigator or health care advocate to the doctor's office staff
- Adopt a preventive care model where primary care doctors screen for diseases and where primary and specialty care are better coordinated
- Some people said they are living their ideal situation

Want more doctors to accept Medicare and Medicaid

*We ... don't know why doctors do not want to accept Medicaid, but whatever the reason is, they need to fix it... because everyone needs a doctor, whether it is a specialist or non-specialist – there needs to be more doctors available out there for the elderly, for the young, pediatrics, whatever it is.
[family member]*

I would like to see the State find a system that would expedite the claim so that the doctors would not feel that they can't take Title 19 because they have to wait six months and go through the whole process of denials and for the elderly.

One thing is the mental health system is over taxed, like there is such a great need to have a consult, and someone to prescribe the meds, and interventions and home care and it's very difficult to find people also who would take the insurance and it's a long wait to get in and also the funding and payment from insurance companies gets reduced so that need to be improved and be taken more seriously

Adopt a preventive care model; PCPs and specialist coordinate

There are so many specialists now; I go to a skin doctor, I go to a foot doctor, I go to an eye doctor, and then I go to one for my glasses; and it seems that there are so many specialists that there is no reason for your primary to check everything anymore.

very rarely you see the doctor look at a person's body anymore, they listen to the heart through the clothes. We have people who are sedentary, people who are getting older, losing weight and becoming frailer and my guess is that there are a lot of skin problems out there and a lot of wound care that is not getting attention, and it goes with the idea of a more thorough examination.

Holistic approach with doctors all in one town or building

I would like for it to be like what I have, everything in the same place, the cancer center and there is psychological help, you know, everything. So, I always have to speak for my friends who couldn't be here who have that problem of having to go to one doctor over there and the other one over there and they have to miss appointments because they don't have anyone who can take them.

I believe like she said if all the doctors were in one place because that way ...there would be more communication with the family, it would be better.

I think the secret too is if you can find a doctor who has a holistic approach and care about all of you and not just about that little piece that he specializes in...

Ideal Health Care and Service Program Themes (Cont'd)

Service Programs

- Some want to choose in-home caregivers from a non-state contracted agency
- A streamlined, easy process for medical and prescription claims
- Confusion about why some people have co-pays and others don't; the majority agreed that co-pays should be eliminated

Ideal Health Care and Service Program Themes (Cont'd)

Service Programs

- The majority of NH residents would rather be home
- More choices for transportation to and from appointments
- Expand medication coverage to include vitamins recommended by physicians
- Dental coverage
- Medical Interpreters available at doctor's appointments

Eliminate co-pays

all of us have worked very hard all of our lives and sometimes we get into a situation where I can't afford the two or ten or fifteen dollar co-pay and you know that to me it's not fair...if it weren't for my pharmacy I would have to pay it right away, fortunately they let me pay it at the end of the month but it even that it's very hard

It would be nice if they cut down on the co-pay. \$10 dollars some doctors or \$20 dollars, and naturally we are all on a fixed income

I have [skipped a doctor's visit] because I could not pay, I didn't go because I couldn't pay it, I think it should be cut out... the co-pay is a stop-wheel because they asked for the co-pay and [I say:] "I don't have it" [and they say:] "sorry, but without co-pay we can't see you" if there were no co-pay you wouldn't have that problem

More choices for transportation

Number one would be transportation issues ideally; they only have that one company that you have to go through the company to get anything under Medicaid for transportation.

One time when I was in Waterbury waiting for them to pick me up I called them and the man said to me: "I don't care how long you have to wait" and hung up the phone, they were supposed to pick me up at four o'clock and they did not get there until ten after five.

I had to go to the hospital for a thing down my throat the next morning at 8 am, and I was waiting out here... and we were waiting and waiting and nobody showed up... they insisted they were there, and it had to be rescheduled...and you know you can't do that, and of course, the doctors are not going to be okay with that either

Need for medical interpreters and dental and vitamin coverage

I would be grateful if there were interpreters when I go to the doctor because there are no interpreters so when I go to the doctor I come back home without any information when the purpose was to get information about my health and I don't get any information.

I'd like to see that as part of the system because people like [name] who are only on vitamins, that is a preventative thing and that is saving a lot of money down the road in terms of what the state will pay for prescription drugs and that should really be included, I mean if you go and take Centrum of one-a-day on your own, that is one thing, but if the doctor says you need B6 or whatever you need you should be able to get them.

I'm on Title 19 and I'm on spend down. Luckily when I went to have my teeth pulled, the hospital sent me a bill for over \$2000. So that took care of the spend down.

Most in NH would rather be home

I got to the point where I was using a walker at home because I have these steps I have to go up and down. With a wheelchair I couldn't do it... And after a lot of discussion, a lot of thought, we've all come to the conclusion that this is the best place for me to be.

I would love to be home. I need too much. I need 24 hour care.

I think everyone in the room would rather be home. That's not even a question. I would love to be home, but I can't live alone. I can't stand up, and would need someone there with me. And I need a lot of medication. I have a son and a daughter, but I think they are relieved because they think that mom is being taken care of.

I was paralyzed and could not walk...I had a big adjustment that I wasn't going home. I can't go home unless I can go to the bathroom...[and to] the kitchen and get something to eat.

Additional Themes

- Positive and negative experiences with medical equipment/assistive technology
- Problems with health care
- Attitudes about health care
 - Patient should not interfere with doctors
 - Individual responsibility

Medical Technology

One of the things that I got through the Medicaid is hearing aids.

...the shoes for the diabetic. I was told that Medicare don't cover it. So the first pair they gave me last year...and now I'm getting a bill for both...pair.

Re: an automated blood pressure reading: They would time it to whatever time you want it.... I find it helpful because I would know if my pressure is high or not. And they will call you.... And she will ask are you alright your pressure is high? We want someone to come and see you.

My sister bought a hearing aid and ... she got the best care ever... and I went to ... get [a hearing aid]....My sister ... said they give you the booklet and you pick from it, and I am not expecting what my sister has for \$4,500 dollars to get it for free, ... I asked him: "do you have any choices?" and he said: "I'm going to give you the smallest one"

I have the medicine machine – it's a nice box and the nurse comes in once a week and fills up my medicine it says, "Time for your medicine, push the button" and out comes the medicine and I say "thank you."

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Problems with Health Care

I had a problem with the diabetes, I had something on the bottom of my right foot and ...the doctor ...told me that I had dried skin and she gave me a cream.... I went again and she sent me to a specialist and the specialist told me: "no, you are not well" and he sent me to another specialist and two weeks later he told me: "we are going to have to amputate the leg"; that was malpractice

I take medication for my blood pressure and the doctor told me: "I am not going to give the pill for the pressure because every time you come here you never have high blood pressure"... and one night I felt something so strange ... and when I got to the hospital my lungs were full of water.

Attitudes about Health Care

I think the less you know the better it is. After you read [a care plan] what are you going to do about it?

I think as patients we have to understand a lot of responsibility falls back to us... we have to consider that when doctors tell us we have to do something, they have a reason

A specialist come check you for a particular sickness, she knows if the patient is ready to go or stay another day..., and there is nothing much the patient can do - just obey the doctor

The world doesn't owe you anything. Yes, we've all worked and we've all put in money I hear ... "I've worked all my life, and I'm entitled to this and entitled to that." You are not entitled to everything. Accept what you get, and accept it with an open heart.

Conclusions & Implications

- On nearly every question, a wide range of experience and opinion
- Satisfied consumers confirm what is working well in the current system
- Dissatisfied consumers point to potential areas for improvement

What is Going Right?

- Many people satisfied with their doctors and medical care
- Transition procedures from hospitals often clear and helpful
- Pharmacists are frequent, reliable source of information and counseling about medication
- People with care managers and/or RSCs have far more coordinated services, know where to go for help, have fewer issues

What is Going Right?

- Many families heavily involved in care and care coordination for MMEs, both in the community and in NHs
- When there are alternatives to ER, people willing to use them
- Most people believe their doctors communicate with each other
- Confident of ability to find mental health care

What Needs Improvement?

- Many doctors refuse MMEs as patients; unwilling to accept Medicare and/or Medicaid
 - Some MMEs have been dismissed by long-time providers
- Co-pays for medical services and medications cause confusion and anger
 - Some people forego medical visit or drugs because they can't afford co-pays

What Needs Improvement?

- Transportation issues for medical care
- Missing services including dental, high quality hearing aids, interpreters
- When docs unavailable, most people head straight for ER
- Care provision & coordination for those without care managers or RSCs is difficult and confusing

What Needs Improvement?

- Most people don't know where/how to make consumer complaint
- Families need information & support
- Age, racial/ethnic and other types of discrimination highlight the need for cultural sensitivity

Caveats

- 65+ population may not represent experience and concerns of those under 65
- Some generational/attitudinal differences
 - Passivity – “doctor is always right”
 - “I’m in a wheelchair so I can’t live at home”
 - Heavy reliance on adult children as decision-makers
- Persons in focus groups cognitively intact; dementia experience largely unexplored

Ideas for Future

- Written care plans viewed favorably; involve family members *when desired by consumer*
- Improve access by incentivizing more doctors to accept MMEs
- Re-consider co-pays
- Explore solutions for dental, hearing aids
- Include consideration of family caregivers
- Include a counseling role for pharmacists
- Ensure cultural and age sensitivity

Contact Information

Julie Robison, PhD

Associate Professor

jrobison@uchc.edu

860 679-4278

Noreen Shugrue, JD, MBA, MA

Pamela Higgins, MS, MPH

Kelly Ruiz, MA

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