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Original Research

Medicaid consumers' views on health and control of health

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Abstract

Objective: Medicaid enrollees in the United States are among the poorest and sickest of the population. Meeting their health needs can be difficult, in part due to their vulnerability. Little is known about how Medicaid beneficiaries view their health, the healthcare delivery system, or their own ability to participate in activities or actions that would help them control or improve their health. This qualitative study used a combination of individual telephone interviews and in-person focus groups to explore Medicaid beneficiaries' views of their health.
Method: Instrument development was informed by theories of health and health behavior. Community liaisons and Medicaid eligibility files were used to identify participants. Thirty-two individual telephone interviews and seven focus groups were conducted, tape-recorded, transcribed, and coded. Themes and conclusions were generated by consensus among the study team by an iterative process.
Results: Beneficiaries described health as a life experience, as a function or action, and with respect to the healthcare system. The ability to control health was associated with the availability of resources, the influence of family and friends, and the role of God and prayer.
Conclusions: Beneficiaries have many conceptualizations of health. Some individuals do believe that there are some actions they can take to control their health. However, this belief in one's ability to control health is not universal and is subject to a consumer's life experiences.

INTRODUCTION

Nearly 60 million residents of the United States are enrolled in that country's Medicaid program [1]. The Medicaid program, jointly funded and administered by the federal and state governments, provides health insurance and financial access to qualified low-income individuals and families. Medicaid enrollees are among the poorest and sickest of the population, and without this program many would not have access to needed health care services [2]. Meeting the health needs of this population can be difficult, in part due to their vulnerability. Yet, relatively little is known about how Medicaid beneficiaries view their health, the healthcare delivery system, or their own abilities to participate in activities or actions that would help them control or improve their health.

"Health" has been described and defined in a number of ways. Specifically, health has been described in terms of a physical or biological manifestation [3]; the extent to which an individual is able to maintain functioning within their social context [4]; or the state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity," as articulated by the World Health Organization (WHO) [5]. These definitions of health are varied. However, no research has assessed whether consumers, and in particular Medicaid beneficiaries, share these same definitions.

Theories of individual health behaviors classify and explain factors which will influence individual health

actions. According to the Health Belief Model and the Theory of Planned Behavior, factors that can influence an individual's decision to act or engage in their health or health care include an individual's sense of whether the benefits outweigh barriers, a belief in their own competency or ability to take action, and access to necessary resources [6-8]. Individuals with this belief in their ability to act are likely to have a high degree of perceived and actual behavioral control [8].

Focus groups and in-depth interviews with Medicaid beneficiaries were conducted in order to gain an understanding of their definitions of health and their ability to control their health. Such an understanding is key to the successful development and implementation of health promotion and healthcare access strategies for this vulnerable group of individuals.

METHODS

Data collection procedures for in-depth telephone interviews and in-person focus groups, including informed consent, were approved by the University of Florida Institutional Review Board.

Instrument Development

Instrument development for the focus groups and interviews was guided by definitions of health as articulated by Wolinsky and Zusman [9] and WHO [5], as well as constructs within theories of health behavior derived from the Health Belief Model[6] and the Theory of Planned Behavior [7, 8]. The goal of this research was to capture beneficiary sentiments and opinions about what health means to them and their ability to "control" their health. The questions used in this analysis are included in Table 1.

Table 1. Questions of the Definition of Health and Control of Health

Question	Probes
What does being in good health mean to you?	Describe health When you hear the word "health," what does it mean to you? What does good mental and physical health mean? Describe what is it like to not be healthy? What role does faith and spirituality play in being healthy? Describe own health and/or that of child How would you describe your health or your child's health? Do you have any chronic illnesses? How do you feel today? What words would you use to describe how you feel today?
What does control of health mean to you?	Give examples of instances when you have been able to control your health. Instances when you can't control your health. Do you have examples of when people or you have tried to control their health—but failed or succeeded? Do you believe personally, that controlling your health is something you can do? Is this something that other people can do? Give examples. Does cost impact people's ability to be healthy? Why or why not? How much control do you have over the health of your family? Does taking care of your family impact how you are able to take care of yourself?
If you wanted to change the way you take care of yourself in the future what would you do?	Describe how you would achieve this change. Is there something specific you would like to change or do differently to improve your health or your families' health? Have you tried to change or do this differently before? Did you succeed or not? Would you try again, why or why not? Could you do it on your own, or if someone gave you money to do it would that help, would that make you change the way you treat your body? What other things would help you change or improve the way you treat your body?

Wording and content were refined after conducting an initial pilot focus group with Medicaid beneficiaries. During the pilot focus group, it was noted whether the participants misinterpreted questions, and they were asked to suggest alternative language and make recommendations for additional questions. An iterative process, typical of qualitative research, was used to continuously revise the instrument based on participant responses, interviewers' observations, and team analyses of data.

Participant Recruitment and Data Collection

Focus groups and individual in-depth telephone interviews were conducted with adults and parents of children who were enrolled in the Medicaid program in the state of Florida. Community liaisons posted flyers and used personal contacts to recruit participants to focus groups. The focus groups lasted approximately 45 to 60 minutes and each participant received a $20 gift card.

Eligibility files from the Florida Medicaid program were used to identify individuals for telephone interviews. Recruitment letters were mailed to randomly selected beneficiaries. The letters were followed up with phone calls to schedule telephone interviews. After the completion of each interview, participants were mailed a $10 gift card. Respondents were recruited and interviewed until it was determined that a point was reached where no new information was being collected. Interviews and focus groups were audio recorded and transcribed verbatim. All participants provided verbal informed consent prior to participation in the study.

Table 2 describes the race and gender characteristics of beneficiaries or parents of beneficiaries who participated in the study. There were 32 participants for individual interviews, and 57 individuals participated in 7 focus groups.

Coding and Thematic Development

Using the instrument as a guide, an initial set of codes was developed. Based on an iterative process, these codes were refined and descriptive sub-codes were developed in order to best catalog the essence of the data. Then, for each general code and sub-code, each study team member (authors) utilized *Atlas Ti 5.0* to aggregate quotes and statements [10]. Team meetings were used to gain consensus on codes and themes and to generate study findings and conclusions.

FINDINGS

Beneficiaries framed health and control of health in a number ways, and several content areas were identified, including a general understanding of health, health as a life experience, health as a function or action, health defined based on the healthcare system, dimensions of health, and the ability to control health. Table 3 describes and lists how Medicaid beneficiaries conceptualized their health and control of health along with subcategories within each broad category.

Table 2. Characteristics of Study Participants

	Focus Group		Individual Interview	
	Number	Percentage	Number	Percentage
Gender				
Female	50	88%	14	44%
Male	7	12%	18	56%
Race				
White	18	32%	11	34%
African American	29	51%	15	47%
Hispanic	8	14%	2	6%
Asian			3	9%
Other	2	4%	0	0%
None specified	0		1	3%
Chronic Condition	NA	NA	25	78%
Total Sample	57	64%	32	36%

Table 3. Thematic Classifications

Theme	Sub-Themes
General understanding of health	Healthy Not Healthy
Health as a life experience	Condition
Function or action	Things you can do Things you cannot do
The healthcare system	Role of clinicians and the medical care system
Dimensions of health	Mental Physical Spiritual
Ability to control health	Individual ability Role of others such as family and friends Role of clinicians and the medical care system Money and resources God, prayer, and state of mind Strategies for remaining or regaining health

General Understanding of Health

Beneficiaries' general understanding of health was based on their descriptions of what they considered to be healthy and not healthy. Healthy was defined as "life" and productivity to some, while others defined it as not having to go to the doctor and having no need for medications. An example of how participants typically noted their concept of being healthy follows:

Health means, it's your life, when you hear the word health you are talking about your life. If I am healthy enough to live, a healthy human being, am I healthy enough to be productive to the world. . .

Descriptions of what it is like not to be healthy include the following statement:

You have poor health you become confused, you're crazy, you do crazy stuff, you know, you are not productive to the world if you don't have health.

Health as a life experience

Health was often defined according to a condition experienced throughout life. One example of how someone described health as a part of their life experience is illustrated below:

Something I've never had in my life. Only for the first 6 months of my life, I was a healthy baby, and after 6 months, I've been sick all my life. The word health in my life is nothing that I've never had.

Health as a Function or Action

Health was also defined according to functions or actions that individuals could do or not do. For example, "health means being able to take care of yourself," "for my child…health is doing exercise, walking, playing around," and "it means that I can get around and do things for myself continuously and not have to depend on nobody to come and take care of me" were some of the functional descriptions individuals used to describe health. One individual described health in terms of a social life: it would be something like walking on the beach with a six pack … a nice chick [woman] walking with me you know.

Health Care System

When talking about health, some individuals framed their comments in terms of the healthcare system. They did this by discussing the role their clinician or the healthcare system played in their health. Clinicians were viewed as key sources of information and instrumental in keeping the beneficiaries healthy by making suggestions and checking their health status. For example, "good health means to me that I see a psychiatrist that keeps me balanced and centered and on track" was one statement used to relate health and health care.

Dimensions of Health

The interview protocol specifically included probes focused on the specific spiritual, physical, and mental aspects of health. Physical health was defined by beneficiaries primarily in terms of activity level. As an example, these individuals responded that physical "health is doing exercise, walking, playing around" or that "you can do just about anything you want to do." Individuals defined being mentally healthy as being happy as in the following quote: "being mentally happy is not worrying and being able to figure things out for myself."

Spiritual health was defined in somewhat abstract terms as "being in tune with the world," "finding answers to life," and "having faith in God." Some discussed their current spiritual health in different ways which generally consisted of the following description:

My spiritual health, oh my goodness, is good... I have found all the answers to life as far as I'm concerned because of my faith….Well I know there is a God. He took it [cancer] away.

Ability to Control Health

Respondents were asked about whether they thought they were able to "control" their health or if they knew what actions were necessary to control their health. Individuals identified five primary factors that facilitate control of health: (1) their individual ability, (2) the role of others, such as family and friends, (3) the role of clinicians and the medical care system, (4) money and resources, and (5) God and prayer.

Individual Ability. Individuals regarded control of health as their personal responsibility. Some respondents were generally empowered to control their own health and spoke of examples where they changed their lifestyle or behavior, including, "I am the best one to judge of what I want and who I want . . . what I need," and the following:

I am going to give you an example of controlling my health. I used to smoke. I smoked cigarettes for 8 years . . . woke up in December of last year and I told myself I am going to quit smoking cigarettes and I quit smoking cigarettes.

While control of health is regarded as personal and individualistic, many acknowledged that it is very difficult to do and that they lacked the ability. In some ways, their comments could be thought of as fatalistic, as illustrated by the following exchange:

Interviewer: Do you have control over your health personally?

Respondent: No.

Interviewer: Why is that?

Respondent: Not now I don't.

Interviewer: Have you had in the past, do you think?

Respondent: Maybe when I was younger, if I had lost weight, knew more than I know now. Change my living and eating habits.

Interviewer: You don't think you can do these things now?

Respondent: Well, the damage is already done, so you can't undo what's already done.

Role of Others Such as Family and Friends. While some individuals did not indicate the degree to which their own health is controlled by factors other than themselves, many did recognize that they may need help and so seek information to gain control of their health. It is at this point that individuals rely on others, including their physicians, nurses, family members, and friends, to provide information and encouragement. Individuals also expressed the need to control themselves: "I try to control it myself, but if I can't control it, I see if I can get help." Other comments regarding control of health included the following: "someone was helping me . . . encouraging me to eat the right food and stuff . . . like somebody to push me. If I try to do it on my own, it is not working."

Money and Resources. Money, or lack of money, affects the ability to control health in several ways, including the purchasing of healthy foods, going to the doctor, and buying medications. The high cost of purchasing healthy foods was cited as the main effect of lack of money on the ability to control health.

To eat healthy it cost more than just going to buy a bag of potato chips or going to McDonalds. You know they got the dollar menu but when you got to eat healthy is like you have to spend more money to eat healthy.

Beyond having enough money to purchase healthy foods, going to the doctor, and purchasing medications, many individuals were simply overwhelmed with the cost of living in general. Worry about paying bills ultimately affected their mental health status.

If I got a bunch of money I wouldn't have to worry about my losing my house and that I think would, instead of taking all this medication I take, it might calm me down you know, and make me feel better about myself . . .

God, Prayer, and State of Mind. Although control of health is regarded as very individualistic, faith in God had a profound impact on an individual's perceived ability to control their own health. Some individuals considered themselves subject to God and His will for them, and had faith that God would take care of them. Other individuals who described themselves as being sick or ill noted that being unhealthy or unwell is a "state of mind." These individuals indicated that they were not going to worry about their illness and that they were going to live their lives as best as possible. For example: but I am not going to let my weakness and my sickness bother me because I stay walking and I stay going, you know, stay going everywhere, but the pains just come and go. And I am not going to let my pains bother me.

This "state of mind" view of health has a spiritual dimension as many participants indicated that faith in God through prayer enabled them to maintain positive

attitudes: "I'm fine, I'm fine, and it's in the hands of God."

Strategies for Remaining Healthy or Regaining Health. Individuals also identified strategies for remaining healthy or regaining health. Overwhelmingly, when asked about strategies to remain healthy or to regain good health, beneficiaries focused on the role of various actions such as changing nutrition and diet, taking medications and going to the doctor, and, to some extent, physical activity and exercise. Many of the phrases used to define health reflect actions to maintain health including having breakfast, going to the doctor, exercising, and eating well.

DISCUSSION

This paper sought to capture Medicaid beneficiaries' definitions of health and their beliefs related to their ability to control their health. Findings have important implications for health policy and programmatic changes aimed helping beneficaries improve and take charge of their health.

The first implication is that individuals have many conceputalizations of health, and they recognized that being healthy (or being unhealthy) can impact quality of life, well being, and the ability to function in society. This has ramifications for the kinds of health promotion programs and information offered to individuals. For example, for some, the messaging may need to focus on how improvements in their physical health (e.g., weight loss) may improve their spiritual health, mental health, or ability to function in society.

Second, not all participants believed that health can be changed or manipulated in some way by their own actions. The findings indicate that some individuals do believe that there are some actions they can take to control their health. These people are able to control their health by interacting with the healthcare system, by their spiritual or mental perspective, or through specific actions or strategies.

However, this belief in one's ability to control health is not universal and is subject to a consumer's life experiences. For example, the beneficiary who was born with ill health felt that his health status is something he cannot change. Such an individual who feels helpless or who has a fatalistic attitude may be less likely to respond to programs aimed at beneficiary empowerment. In this instance, a strategy might be to focus on helping the beneficiary understand ways to improve their quality of life, rather than a focus on improving health.

Other beneficiaries may believe they have the ability, but the "tools" they use (e.g., religion, spirituality, friends, and family) are not necessarily supported by or described in policy and programmatic interventions. In this instance, financial incentives coupled with programs that include an individual's support system may be the most effective approach towards empowerment.

A third implication is that access to good information and incentives would likely encourage action through active decision making and participation for some beneficiaries. For example, those participants who indicated that control of their health is their personal responsibility may be even more empowered to engage in healthy activities and consumer choice. Similarly, those who are already aware of strategies to improve health could be open to receiving new information and change their health behaviors accordingly.

A key limitation to this study is the recognition that individuals who agreed to participate may have been motivated by prior experiences with Medicaid and thus had a greater desire to tell their story. To counter this bias, questions and probes were framed in neutral tones and two approaches were used to recruit study participants.

Despite this concern, this study suggests that Medicaid beneficiaries' beliefs may have some impact on their ability and desire to make and act on decisions related to their health and health care. As policymakers continue to look for ways to empower individuals to take charge of their health, program design should consider the multidimensionality of health, whether individuals think they can control their health, and the existing strategies they may choose to control their health.

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