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Authors

Shapiro, Johanna
Mosqueda, Laura
Botros, Danny

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A caring partnership

Expectations of ageing persons with disabilities for their primary care doctors

Johanna Shapiro^a, Laura Mosqueda^{a,b} and Danny Botros^a

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Background. The population of individuals who are ageing with a disability is growing rapidly, yet we know little about their views of their primary care and family physicians.

Method. In this qualitative study using a modified form of life history interviewing, 30 older respondents with a variety of disabilities discussed their past and current relationships with physicians.

Results. Data analysis identified as the primary theme of these interviews the importance of establishing a caring partnership between patient and physician. Important subthemes included physician avoidance of assumptions and stereotypes about persons with disabilities, physician commitment to patient well-being balanced by a capacity for keeping the disability in perspective, and the relationship between the need for physician specialized knowledge and the necessity of acknowledging patient expertise. Certain patient characteristics such as self-reliance and assertiveness also emerged as significant influences.

Conclusion. A partnership with primary care/family physicians that communicates concern while avoiding stereotyping and recognizing patient expertise is important for many patients ageing with a disability.

Keywords. Ageing, disabilities, doctor–patient communication, doctor–patient relationship, patient satisfaction.

Introduction

For the first time in history, people who have an early or mid-life onset disability are living into old age. Their attitudes toward health care and the physician–patient relationship are shaped by many factors: the era in which they acquired the disability, their age at onset and their current age, to mention only a few. However, even though this population is growing at an exponential rate,¹ and even though they require more health care than their non-disabled counterparts,² there is virtually no information available regarding these patients' attitudes toward and relationship with their primary care and family physicians. Yet, as the life span of individuals with disabilities normalizes, so that people with

disabilities are living longer, it becomes of increasing interest to discover how this population relates to its primary care physician caregivers as it ages. Further, since in the general population it is estimated that physicians should add one chronic disease for every decade of patient life,³ it is likely that the attitudes of ageing persons with disabilities will have something to teach primary care and family physicians about caring for older persons generally.

The large literature on doctor–patient interactions and patient satisfaction finds that physician qualities, including respect, kindness and friendliness,⁴ are important to patients generally, as are specific communication skills.⁵ Clinical competence also matters to patients.⁶ Disturbingly, patients regularly report that their visit-related expectations are disappointed,⁷ and unmet expectations have been shown to contribute significantly to patient dissatisfaction.⁸ In contrast, a participatory decision-making style that consults patients about their own health care has been significantly correlated with patient satisfaction.^{9,10} Patient satisfaction is also related both to continuity of care^{11,12} and to characteristics of the doctor–patient relationship.¹³ Patients of all ages consistently rate satisfaction with

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^aDepartment of Family Medicine and ^bProgram in Geriatrics, University of California Irvine College of Medicine, Orange, California, USA. Correspondence to Johanna Shapiro, PhD, Department of Family Medicine, UC Irvine Medical Center, 101 City Drive South, Orange, CA 92868, USA; E-mail: jfshapir@uci.edu

their own physicians higher than that with physicians in general.¹⁴

One finding consistently reported about older patients in particular is that they tend to indicate more satisfaction with care and with their physicians than other age groups.^{15,16} A possibly related claim is that older patients are less assertive and prefer the physician to 'take charge'.¹⁷ Why this might be so is unclear, although some investigators have speculated that generational characteristics of stoicism and respect for authority typical of the 'greatest generation' play a role,¹⁸ while others have suggested a reticence to complain and openly share feelings among older Americans.¹⁹ Although one provocative study suggests that older patients care more about technical ability than interpersonal skill in their physicians,¹⁵ other research emphasizes the importance of personal interaction and caring, empathetic, compassionate physician qualities.³ When older patients do express concerns about their health care, they tend to focus on the doctor being in a hurry, not adequately explaining medical problems or using unnecessarily complex technical language, acting in a condescending manner and lengthy wait times.^{3,15}

Research focusing on the satisfaction of disabled patients with their doctors suggests that although, as with the population in general, patients with disabilities express fairly high satisfaction with physicians, they also have significant concerns. In fact, disability is considered a risk factor for dissatisfaction with health care.²⁰ Patients with disabilities often express frustrations about unmet health care needs,²¹ and lack of health promotion services.²² Another common worry is that their primary care physicians are insufficiently knowledgeable about their disability²³ and that, as a consequence, the patients themselves often must provide education and expertise.²⁴ Physical access problems are also of concern, including lack of transportation,²⁵ architectural barriers and difficulties with exam tables.²⁶ Research has further documented negative physician attitudes toward disabled patients²⁷ and even patients being refused medical care because of a disability.²⁸ In keeping with studies of ageing patients, research suggests that older patients with disabilities are likely to report greater satisfaction with both technical information and affective care than are younger patients.²¹

Taken as a whole, the literature suggests that older patients are highly satisfied and fairly quiescent, with as much concern for physician technical competence as for interpersonal qualities. Their dissatisfaction focuses on long wait times, superficial encounters and inadequate explanations of medical conditions. Patients with disabilities may be somewhat less satisfied, and have particular disability-related apprehensions regarding both physician attitudes and competence. Because of the lack of previous research with the population of ageing persons with disabilities, our study adopted a qualitative approach to investigate various aspects of

the role of disability in the lives of older persons. This article reports on findings pertinent to respondents' views of physicians and the primary care/family doctor-patient relationship.

Methods

Participants and sampling strategies

Participants were recruited primarily from a larger ongoing study on the natural course of ageing with disabilities. Inclusion criteria for entry into the qualitative study were age >50 years and time living with disability \geq 10 years. A purposive sampling strategy was used which emphasized both identification of 'typical' cases, or individuals who seemed representative of the larger study sample in the eyes of the recruiter, as well as individuals who represented variations or exceptions, and might present disconfirming data.²⁹ The data collection process was terminated when theoretical saturation had been reached, i.e. when no new theoretical constructs were emerging from interviews and a point of redundancy had been achieved. Five participants entered the study through a snowball technique³⁰ of referral by another respondent. A total of 30 individuals participated in this research, although the data from two individuals were eliminated from the final analysis because they were younger than 50. Patient demographics are listed in Table 1.

Question route and procedures

Data were obtained through an open-ended question route³¹ developed by JS, based on the concept of life history narrative. Life history narrative uses a conversational interview approach to allow the patient to tell the story of his or her life without being directed by the researcher toward a narrow, reductive agenda.^{32,33} Life narrative interviewing encourages exploration of reminiscences in a way that examines perceptions of mastery or competence in dealing with stressful life events and ability to integrate those events within the whole life of the respondent. It is a useful technique both for eliciting content stories of an individual life and for placing perceptions, values and opinions on a particular topic within the context of that life.³⁴ The interview utilized in this study asked respondents to (i) tell a little about themselves, including what was most important about them, how others would describe them, and a memorable negative and positive event in their lives; (ii) discuss the impact of their disability on their life over time; (iii) describe their current medical problems and conditions; (iv) talk about their relationship with their primary care/family physician now and in the past; and (v) make recommendations to physicians regarding how to improve the doctor-patient relationship. These guiding questions are typical ways of obtaining personal narrative related to explicit subject matter.

TABLE 1 Respondent demographics

Gender	
Male	6
Female	22
Ethnicity	
Non-hispanic white	27
Native American	1
Age	
Range	51–82
Mean	63.43
50s	12
60s	9
70s and 80s	7
Education	
High school/some college	16
College	7
Post-college	5
Marital status	
Married	17
Widowed	3
Divorced	8
Diagnoses	
Post-polio syndrome	12
Cerebral palsy	4
Spinal cord injury	3
Stroke	3
Miscellaneous (multiple sclerosis, rheumatoid arthritis, fibromyalgia)	5
Age of onset	
Range	0–68
Mean	22.46
0–9 years	10
10–19 years	6
20–30 years	5
35–65 years	7
Years living with disability	
Range	10–78
Mean	40.93
Primary care physician specialty	
Family physician	12
General internist	10
Geriatrician	1
Obstetrics–Gynaecology	1
Unspecified	6

Participants were given a choice of location for the interview. Most were interviewed in their homes, although several preferred to be interviewed at the university where the research was conducted. Interviews lasted between 1.5 and 2.5 h. All interviews were videotaped. In addition to the lead interviewer, an undergraduate student usually participated in the interview, and conducted the videotaping. For portions of many of the interviews, family members (most often spouses, but also adult children and other relatives) entered the room and contributed comments. In keeping with the theory of life history interviewing, the atmosphere was informal and relaxed. Follow-up telephone interviews were conducted with eight individuals for the purposes of clarifying statements in their original narratives. Transcriptions were made of

aspects of each interview relevant to the study questions (because of the informal nature of the interviews, respondents sometimes discoursed at length on topics not pertinent to the focus of this study, and limited funds precluded transcription of this material). Between them, two of the authors (JS and DB) participated in all but two of the interviews (these were completed by other student–interviewer teams). All authors viewed the tapes and made extensive notes on their observations, which were then reviewed and discussed by the research team.

Data analysis

Data from the interviews were analyzed using a content analysis approach based on grounded theory constant comparative analysis.^{31,35} This system of analysis is well established in qualitative research, and is one familiar to the authors. It provides conclusions that satisfy criteria of trustworthiness, coherence and credibility.³⁶ In this method, ideas or phenomena are first identified and flagged (open coding), then fractured and reassembled (axial coding) by making connections between categories and subcategories. Finally, categories are integrated to form a single overarching conceptual category (selective coding).^{37,38} The conclusions reached below represent the efforts of the research team to identify consensually first key words and phrases from the transcripts and tapes, then reorganize these into larger conceptual categories, and finally regroup them into an all-encompassing theme.

Results

A caring partnership

Like many older patients, respondents in this study generally liked their primary care/family physicians. However, in contrast to other published reports of older patients, although consistent with reports of patients with disabilities, they tended to be quite critical of physicians in general, and to express many disappointed expectations regarding their relationship with physicians over the years. Within this context, the main theme identified in the study was respondents' aspirations to develop a caring partnership with their primary care/family physicians. This partnership was defined along several different physician dimensions: (i) avoidance of assumptions and stereotypes about persons with disabilities; (ii) personal commitment to the patient and eagerness to place his or her disability within the context of overall life priorities; (iii) possession of specialized knowledge about disability; and (iv) acknowledgement of patient expertise, including taking the patient seriously and openness to learn from the patient; as well as certain patient characteristics that supported the desire for partnership. Although on the surface these categories appear simply to subsume generic qualities

that any patient might seek out in a physician, a careful analysis suggested that all were distinctively framed by the respondents' experiences of living for many years with disability.

Avoidance of assumptions and stereotypes about persons with disabilities

Respondents stressed the importance of their primary care/family physicians not making assumptions about who they were, or what they could or could not do, based on their disability. Two respondents with spinal cord injuries recounted disturbing examples of physician insensitivity.

“One time when my family doctor watched me transfer, he said, ‘Wouldn’t it be easier if you didn’t have any legs?’ ” (MJ)

“The first time I met my primary care internist, he told me I was lucky to be walking around [this respondent can walk for limited distances with crutches]. He didn’t mean to be insensitive.” (CB)

Respondents frequently stated they wanted to be treated ‘normally’, not as a person with a disability.

“We’re like everybody else. Don’t treat me any different and don’t make assumptions.” (CB)

“We don’t want doctors to be fawning. We don’t want pity—we pick up on it fast. We don’t need pity.” (DB)

Respondents with cerebral palsy or multiple sclerosis were indignant at physicians who made assumptions about their mental capacity based on their speech or appearance. Respondents wanted their physicians to see them as people, not just as a disease or disability. They wanted to be recognized as unique individuals, not simply as examples of a textbook condition.

“I want doctors to know what makes me tick, know a little bit about my personal life. If they have this information, perhaps they can detect that something is bothering me, then the reason I’m there can be resolved in a better way. Remember the patient is a human being first.” (CN)

“Doctors have this wall—this is what the textbook says, there’s no variance. I’ve run into that a tremendous amount. Handicapped people don’t have textbook bodies.” (JC)

Respondents hoped their physicians would take their whole body, mind and spirit into consideration, not simply the diseased or affected parts. Along similar lines, patients who appeared most satisfied with their physicians also tended to have had longer continuity relationships with this provider.

Several respondents expressed most trust and confidence in physicians who had some personal experience of disability. They noted that these physicians tended to be less likely to hold stereotyped assumptions

about persons with disabilities and to be more caring and understanding.

Commitment and perspective

All patients probably hope for personable doctors, and our respondents also appreciated physicians who were ‘pleasant’, ‘nice’ and ‘friendly’. However, respondents in this study also had much more precise qualities in mind when evaluating their primary care/family physician that were strongly influenced by their life experience as persons with disabilities. Interviewees who were satisfied with their doctors felt these physicians “had their interests at heart”, really thought about how to make things better for them, “tried to help in any way they can” and were ‘caring’ and ‘compassionate’.

“My primary care physician is an internist. I can tell him anything. We have a good rapport. He’s a wonderful doctor. He can tell how I’m doing just by looking at me. I like him. He trusts me, and I trust him. I have to drive a long way to see him, but he’s so understanding, I wouldn’t change.” (EH)

They also appreciated physicians who were ‘reassuring’, ‘not alarmist’ and ‘low-key’, possibly a reflection of their desire to have their disabilities and other ailments placed within the perspective of their long and full lives. Several patients pointed out that a sense of humour could be helpful in the doctor–patient relationship, and a few recounted incidents of joking with their physician about their disability. In contrast, disliked doctors were described as ranging from ‘not caring’ and ‘dismissive’ to ‘arrogant’, ‘rude’ and ‘with a god-complex’. In the partnership model, there was no place for physicians who assumed they should always have the final say about their patients.

“Doctors aren’t god. Just because he has an MD after his name, he’s not perfect. Sometimes he’s less perfect than I am.” (JB)

Specialized knowledge

These ageing respondents with disabilities hoped that their primary care/family physicians would demonstrate specialized knowledge about their specific disease or disability or at least have an interest in acquiring such knowledge. Respondents valued primary care physicians who had some expertise about or familiarity with conditions such as cerebral palsy, multiple sclerosis, spinal cord injury or post-polio syndrome. However, only a minority of respondents felt that their physicians actually possessed this type of proficiency. More commonly, respondents expressed frustration at the lack of knowledge about disability that they encountered in their primary care providers. This was a concern expressed by patients across disability types.

“Doctors are not willing to acknowledge post-polio syndrome exists. They don’t even assess a patient to see if they have a history of polio. They should

educate themselves, patients shouldn't have to educate them." (BD)

"Since my injury, doctors look to me for information on spinal cord injury. They don't know that much about it. A doctor told me, 'I just ask them [patients with SCI] so I can learn from them.'" (MJ)

"Doctors would like to fix me, but they don't know how. They're frustrated because they're supposed to know what to do. I'd feel better if doctors honestly admitted they didn't know what to do or how to help." (JG)

A related theme expressed by post-polio syndrome patients was that because they were often perceived as 'a dying breed', doctors had little interest in their care.

"We're extinct, we're a waste of time. Doctors think they should be working on something else" (NM)

"There's not a lot of research being done. The rationalization could be that this generation will die off so they don't have to worry about it. This group will eventually be faded out of the world so they won't be bothered with us." (BD)

Acknowledging patient expertise

This concept involved taking the patient seriously (by listening to the patient and assessing their symptoms seriously) and willingness to learn from the patient. Respondents hoped physicians would listen to their ideas about diagnosis and involve them in the development of an appropriate treatment plan. Most respondents subscribed to the notion that patients with disabilities know more about themselves in relation to their medical problems than do doctors, and that the primary care/family physician in particular should respect this self-knowledge.

"Doctors should take patients seriously, listen to what's been happening to them physically. They should believe the patient, not assume it's something the patient made up." (JG)

Respondents elaborated that this meant paying attention to all the patient's observations and hypotheses, and even, in the words of one respondent, "believing the patient over the chart."

Careful listening

All patients want doctors who are good communicators. However, our respondents looked at physician communication skills specifically for evidence that they were willing to respect the patient's own insights. One sign of this respect was doctors who would answer their questions fully and provide thorough, but comprehensible explanations. Many mentioned that the most important quality in their primary care/family

physician was the ability to 'listen'. This seemed to mean really listening to what the patient wanted to say, rather than simply waiting to express their own preconceived (i.e. textbook) ideas. Conversely, the most frequent complaint respondents made of 'bad' doctors was 'not listening'.

"Doctors listen for a short time, then cut you off. They start ordering things, when they haven't even heard your symptoms. They don't really listen. They tend to make their decisions before the patient is even finished." (AC)

"Doctors are generally not good at listening to what patients know about themselves, about their own bodies." (BD)

"I know my body better than the doctor does. If they listened a little more to patients describe their problems, it would be better." (NM)

Thoroughness

Scrupulous evaluation of patients' symptoms and not rushing emerged as another important sign of taking the patient seriously. One of the vehement complaints of respondents was the perception that their primary care/family doctors were always in a hurry, had insufficient time to spend and were therefore superficial in their diagnosis and treatment, eager to get the patient out the door. Since respondents were sceptical that physicians had expert knowledge about their disability-related medical conditions, this rushing made them feel particularly vulnerable.

"Our previous doctor was worthless, a double-parked triage doctor." (FB)

"Doctors don't have time to really research your condition. They do whatever they can to pass it off, rather than find out what's really going on." (PM)

Being dismissive or patronizing about a patient's concerns was a black mark against any physician.

"Those lovely doctors would say, 'You're a woman, so you must be a complainer, a hypochondriac. There's nothing wrong with you, it's all in your head. Go exercise. Maybe it's menopause.' Nobody thought of post-polio syndrome." (KH)

Patient characteristics

Respondents referenced several personal qualities in themselves that made partnership with their primary care/family physicians particularly important: specifically, self-reliance, self-responsibility and assertiveness.

Many respondents, especially those at the older end of the sample and who had lived with a disability for a long time, believed that they had primary responsibility for their own health. Individuals with post-polio syndrome and spinal cord injury in particular demonstrated

a tendency to state, “I take care of myself” or “I rarely go to doctors”. This attitude is consistent with what has been labelled the ‘post-polio personality’,³⁹ characterized by high achievement and assertiveness.

“We’re not doctor people . . . we just wait till something breaks down . . . I don’t worry about minor things, and I always try to fix myself before going to the doctor.” (JB)

“I feel like I have to be my own doctor. It’s mostly my responsibility to keep control of my own health.” (CB)

“Doctors are just humans, they can make mistakes. It’s not a good idea to leave everything up to the doctor. I’m the one responsible for my health care.” (DH)

Respondents who had lived with their disability for a shorter length of time or who were younger tended not to express this autonomous attitude.

Respondents often reported adopting a strongly assertive, even confrontational stance in relation to their physicians. Many noted that they did not rely on their physician’s input, but did their own research on their medical conditions, then tried to educate their physicians about what they learned. They stressed the importance of not being afraid to ask questions and to challenge recommendations and procedures they felt would not be beneficial.

“The patient is the person in charge. Doctors forget about that.” (JC)

“It’s important to be part of your own health, taking an active part. Treatment is a joint effort.” (AC)

“I’m not afraid to ask questions. At my age, I’m kind of cued in. I’m the one controlling the situation.” (PM)

Advice for primary care/family physicians

When we specifically asked respondents to provide advice to physicians caring for older patients with disabilities, their answers generally reflected the qualities and concerns listed above. By far the largest number of patients urged physicians to take patient self-knowledge into consideration, accept patient concerns as legitimate and not to judge patients negatively or label them as complainers. They also reminded doctors to see their patients as human beings, listen to them and behave in a caring and compassionate manner.

Discussion

In many ways, these older individuals with disabilities reflected trends among the patient population at large, as well as among older patients. They were generally satisfied with their health care, and particularly with their own primary care/family physicians. They were

concerned about good communication with their physicians, and valued interpersonal warmth and caring as well as specialized knowledge and expertise. However, on all dimensions of concern, their views appeared strongly influenced by their experiences over many years of living with a disability. For example, while often frustrated by physician’s lack of knowledge about and sensitivity to their particular impairment, most respondents also expressed willingness, even a desire, to help educate their doctors about their conditions. They tended to see themselves as equal partners with their physicians and held strong beliefs about their disability-related expertise and self-knowledge, which they wanted to be recognized and incorporated by their physicians. For the majority of respondents, their coping skills seemed firmly locked in place after many years of disability, and they wished for the opportunity to convey this knowledge to their physicians. They were generally prepared to be forceful, even confrontational, in getting their health care needs met. Respondents wanted to be seen in all their particularity, and to be taken seriously and treated with respect for who they were and what they had overcome. Of course, such physician attitudes and skills should be present in all physician–patient encounters, regardless of age or ability status. However, it was clear that these respondents believed their disability put them at particular risk for becoming invisible, devalued, and being treated perfunctorily and dismissively by their physicians.

Limitations of this study include the fact that, since those actually interviewed were self-selected in the sense that they could decline to participate, bias may have been introduced in this manner. There is also the possibility that our method of recruitment favoured activist, assertive individuals with a consumerist type of response who wanted a forum to make strong statements about doctors and health care. Those individuals who did not participate may represent a more resigned and apathetic group, who have given up on medical care. One mitigating circumstance against this interpretation is that the research project was presented to potential participants as a study of the effects of disability on ageing, and did not emphasize our interest in doctor–patient relationships, although this topic was mentioned in recruitment. Other study limitations included a lack of ethnic diversity and the small number of men in the sample, which made it impossible for us to explore ethnic- or gender-based interpretive possibilities. Finally, our conclusions are limited by the fact that the study was conducted in a state with a high proportion of managed care. All of these factors must be taken into consideration when construing the meaning of these findings.

Nevertheless, this study suggests the importance of listening to older, disabled patients about their expectations regarding satisfactory health care. Primary care and family physicians who care for an ageing population

with disabilities must be prepared to enter into a caring partnership with their patients by treating them seriously and with respect. They must be willing to admit their ignorance when necessary and have enthusiasm for learning about their patients on both personal and medical dimensions. Incorporating such approaches and skills will be instrumental in achieving a good doctor-patient relationship with a growing subset of the patient populations, ageing individuals with disabilities.

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