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Vitamin D: An Examination of Physician and Patient Management of Health and Uncertainty

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Abstract

Vitamin D has been a topic of much research interest and controversy, and evidence is mixed concerning its preventive effects and health benefits. The purpose of our study was to explore the decision making strategies used by both primary care providers and community members surrounding vitamin D in relation to uncertainty management theory. We conducted semistructured interviews with primary care providers (n = 7) and focus groups with community members (n = 89), and transcribed and coded using the constant comparative method. Themes for providers included awareness, uncertainty, patient role, responsibility, skepticism, uncertainty management, and evolving perceptions. Community member focus group themes included uncertainty, information sources, awareness/knowledge, barriers, and patient-provider relationship. Both providers and community members expressed uncertainty about vitamin D, but used conflicting strategies to manage uncertainty. Awareness of this disconnect might facilitate improved patient-provider communication.

Keywords

communication; medical; constant comparison; decision making; focus groups; health care professionals; health care; primary; health information seeking; interviews; semistructured; nutrition / malnutrition; uncertainty

Interest and controversy regarding vitamin D exist among researchers, practitioners, the media and the public. Whereas physicians estimate that 42 to 64% of the population is deficient in vitamin D (Forrest & Stuhldreher, 2011), evidence is mixed concerning medical benefits of having sufficient vitamin D levels (Rosen et al., 2012; Wang, Manson, Song, & Sesso, 2010). The media coverage of early and nondefinitive research on vitamin D has created a situation wherein both patients and health care providers experience uncertainty, a common experience in situations concerning health and illness (Babrow & Kline, 2000). The effect of vitamin D deficiency is potentially widespread, yet current understanding of vitamin D is complex and ambiguous because of conflicting information. These characteristics correspond to the criteria for high uncertainty outlined by DeLorme and Huh...
(2009), making management of vitamin D in the clinical encounter particularly susceptible to difficulties with communication.

For the reasons elucidated, we explored the perceptions and management strategies used by both health care providers and the lay community in relation to how each group experienced uncertainty surrounding vitamin D. As we analyzed the information through constant comparison, we began to hypothesize that each group’s strategies could be described and characterized using theories of uncertainty management; therefore, we review the literature on uncertainty management theory (UMT) and vitamin D’s potential health effects below.

**Literature Review: Uncertainty Management**

Early researchers argued that uncertainty was an unpleasant experience and that individuals would employ strategies to reduce feelings associated with it (Berger & Calabrese, 1975). Brashers (2001) conceptualized a more complex uncertainty management theory (UMT), perceiving that individuals manage rather than reduce their uncertainty. The uncertainty management process includes an appraisal of uncertainty and a behavioral response that an individual selects from a plethora of strategies.

Similar to Brashers’ view on uncertainty, Babrow and Kline (2000) argued that managing uncertainty is better than simply reducing uncertainty. Response to the appraisal of uncertainty is highly individualistic and depends on the personal relevance, goals, coping abilities, and resources available (Brashers, 2007; Delorme & Huh, 2009). Despite the choices available to an uncertain individual, communication through information seeking and information exchange is the central component to management (Brashers et al., 2000). People can manage uncertainty by using multiple sources of information in answering questions, taking an active role in health care needs, confronting negative behaviors and learning to cope, using social support, and manipulating uncertainty to fit individual needs (Brashers, 2001; Brashers et al., 2006).

**Literature Review: Vitamin D**

Vitamin D has been recognized as an important factor in health outcomes. It plays a role in increasing calcium absorption, prevention of rickets, and prevention of osteomalacia (Reid, Bolland, & Grey, 2007; Wagner & Greer, 2008). Evidence that low levels of vitamin D might be associated with risk for various cancers is inconsistent (Avenell et al., 2012; Chung, Lee, Terasawa, Lau, & Trikalinos, 2011; Lappe, Travers-Gustafson, Davies, Recker, & Heaney, 2007). Researchers have also made the case that low vitamin D levels are associated with diabetes (Mitri, Muraru, & Pittas, 2011), cardiovascular disease (Fiscella & Franks, 2010; Wang et al., 2010), frequency of falls (Bischoff-Ferrari et al., 2009), and cognitive impairment (Llewellyn, Langa, & Lang, 2009).

Despite the potential for vitamin D supplementation to reduce chronic disease and health disparities, study results have not been definitive. Risk reduction effects are inconsistent (Rosen et al., 2012; Shapses & Manson, 2011) and some studies have revealed potential harms associated with high intake or levels of vitamin D (Glendenning et al., 2012; Sanders et al., 2010). These mixed results have led to hesitance in releasing official guidelines for testing, supplementation, and monitoring of vitamin D. The differing recommendations of specialists have induced patient skepticism about any potential benefits (Holick et al., 2012; Rosen, Abrams, et al., 2012). Taken together, conflicting studies have resulted in media attention that has undoubtedly influenced both health care providers and consumers. In this study we used decision making concerning vitamin D as a model of how each group
navigates these conflicting messages to obtain and use new information and communication about a common health problem with uncertain effects of treatment.

Uncertainty Management and Vitamin D

According to UMT, if uncertainty becomes a cause of stress or distress, individuals will attempt to reduce it using passive, active, and interactive strategies (Brashers, 2001). Individuals who employ passive strategies make observations or notice information without actually seeking it. They can reduce uncertainty by any means of gaining information, even unintentionally. A lay person might read an article in a magazine covering vitamin D, or a physician might receive a newsletter with a column on osteoporosis, for example. In the active strategy, people intentionally seek information about the uncertainty-inducing issue. Patients might conduct Internet searches, whereas providers might look up clinical guidelines or ask a colleague as the topic arises in clinical practice. The interactive strategy includes communicating directly with an expert on the subject (Berger, 1979; Berger & Calabrese, 1975). For patients, a discussion about vitamin D with their health care provider might be interactive, and providers could similarly interact with an expert consultant or perform a specific literature review (Brashers et al., 2006). When patients do seek interaction from providers surrounding vitamin D, both must disclose their current knowledge and beliefs and potentially reveal uncertainty to one another (Afifi & Afifi, 2009). Babrow, Kasch, and Ford (1998) identified research on health professionals as an avenue to assist in understanding uncertainty. Provider uncertainty about vitamin D can impact the trust, stability, and treatment decisions they offer patients, creating a communicative dilemma that affects the uncertainty management process for both parties. Understanding where the uncertainty lies and how to manage it can highlight information needed by patients and providers and the best ways to communicate about these uncertainties in patient-provider interactions.

In the spirit of grounded theory approach (Glaser 1992), the original two research questions were open ones: What do primary care providers and health care consumers know about vitamin D, and how do they experience the current controversies surrounding vitamin D? As the data analysis unfolded and the uncertainty management themes became evident, we honed our questions to the following: What are the uncertainties about vitamin D that primary care providers (PCPs) experience; how do PCPs manage their uncertainty about vitamin D; what are the uncertainties about vitamin D that health care consumers experience; and how do consumers manage their uncertainty about vitamin D?

Methods

To explore the research questions, we employed two different research methods between January and May 2011. First, we recruited providers to participate in semistructured interviews. Second, we recruited community members (health care consumers) representing potential patients to take part in focus groups. All participants signed consent forms after the researcher conducting the interview or focus group explained consent and protections for confidentiality. We collected and securely stored consent forms separately from, and not associated with, audio files or transcripts. We removed any proper names from transcripts to preserve confidentiality. The University of Kentucky Institutional Review Board approved all elements of the study.

Provider Interviews

Inclusion criteria included working as a primary care physician, nurse practitioner, or physician assistant practicing within a Southeastern state. We recruited PCPs using purposeful sampling of providers practicing in the specific counties where the community
focus groups took place. Because that restriction proved too limited, we expanded recruitment to include a convenience sample of any PCP member of the regional practice based research network (PBRN) of the state. We contacted providers via phone, fax, and/or email invitations and offered lunch for their office staff and a handout summarizing vitamin D research as participation incentives. In the phone interviews, we used a semistructured interview protocol, and recorded and transcribed the dialogue. Interviews lasted between 22 and 70 minutes. The interview guide (with structure variations based on the level of PCP awareness) appears as appendix A.

Community Member Focus Groups

Recruiting patients from provider offices is difficult because of confidentiality and logistical barriers; therefore, we chose to use lay community members to represent health care consumers who would be typical potential primary care patients. The inclusion criteria included residence in the specified counties and ability to speak English and provide consent. We recruited consumers through announcements at the Cooperative Extension offices of three counties chosen to achieve ethnic and urban-rural diversity in the same Southeastern state. Cooperative Extension is a nationwide educational network that brings research and knowledge of land-grant institutions to people in their homes, workplaces, and communities. The Cooperative Extension Service System is an outreach and engagement program of the United States land-grant university system. Each state and territory has an office at its land-grant university and local or regional offices. Each office houses professional staff, Extension agents, who provide practical research based information and informal education (United States Department of Agriculture [USDA], 2011).

We partnered with Family and Consumer Science (FCS) Extension agents to recruit participants from clientele who participate in adult education programs, nutrition education programs, or other services of the Cooperative Extension Service. The FCS agents prepared and distributed recruitment flyers to community groups. One group consisted of senior center program participants; two groups consisted of members of an outreach educational organization of the Cooperative Extension Service; and three groups were recruited from diverse community members with an interest in vitamin D. Two focus groups took place in urban communities and the remaining in rural communities. The focus groups averaged 14 participants and were approximately one hour in length. The focus group facilitator guide appears as appendix B.

The county Extension offices were the locations, and the fourth author was the facilitator of the focus groups. Participants received lunch and an informational handout about vitamin D. The focus groups followed a semistructured questioning route. We recorded and transcribed the group proceedings. It is important to note that focus group sessions began with the question, “What have you heard about vitamin D?” Some of the conversations proceeded organically to other questions on the focus group interview protocol, but many of the participants asked questions more frequently than they expressed opinions. Thus, we coded both their statements and their questions to provide a deeper understanding of their uncertainty about vitamin D.

Data Analysis

We transcribed interviews and focus groups verbatim from the recordings. For the purposes of reporting the results in this manuscript, we removed filler words (e.g., um, uh) for reader clarity. We organized the data into coding units, or a complete thought expressed by the participants. We first used a grounded theory approach, employing open-ended questioning to allow themes to come organically from the study subjects themselves (Glaser, 1992). We
also analyzed through the constant comparative method, comparing each interview or focus group transcript to previous transcripts, searching for repetitive themes and new themes.

The coding process occurred in four phases. First, the first author examined the data and developed a codebook for the provider interviews and a codebook for the community member focus groups. Specifically, this author coded for emerging themes when they appeared across interviews/focus groups or multiple times within an interview/focus group, exhibiting repetition (Owen, 1984). Second, the first and second authors independently coded the provider interview data, and the first and third authors coded the community member focus groups using the appropriate codebooks. Simultaneously, these three authors coded for any new themes that were not included in the initial codebook. Third, the authors convened to discuss coding and refine the codebook based on their independent coding. Fourth, the authors independently coded the data again using the refined codebook.

Although it is impossible to truly determine saturation, the constant comparison method allowed us to confirm that we were no longer adding themes to the codebook as we ceased recruitment. The themes were different for providers and community members. We present the themes in the order of prevalence for each group.

Results

Providers

Providers (N = 7) included men (n = 2) and women (n = 5) who ranged in age from 33 to 69 years. They were primary care physicians who had been practicing medicine between 3 and 38 years and represented a variety of practice types, including private clinic (n = 2), university based clinic (n = 2), community health center (n = 1), hospital based clinic (n = 1), and long-term care nursing home (n = 1). We identified seven themes in the provider interviews, with up to four subthemes for each. Intercoder reliability was assessed using Cohen’s Kappa, which was acceptable at .88.

Awareness—Awareness of vitamin D was the most prevalent theme in the data (n = 144 coding units out of 554 provider units, or 26%). Three subthemes of awareness also emerged including recency, knowledge and confidence, and sources of knowledge. Participants often mentioned that they had only recently become aware of a need to check and treat vitamin D levels. One PCP said, “Oh, well, I’ve definitely been checking vitamin D blood levels a lot more frequently, and I don’t think I ever thought about it until the last three years or so.” Another said, “I have been checking it [vitamin D levels] for about one year to one year and a half.” The knowledge that providers held about vitamin D focused on the causes of deficiency and the testing and treatment for it. In general, the providers reported feeling confident about select pieces of knowledge. A PCP stated:

I do routinely check it [vitamin D] and routinely; if it is under ten, then I’ll prescribe 50,000 once a week and then recheck it. If it’s over that, I usually, well, patient to patient, but I’ll have them take varying amounts of vitamin D. If it is close to being 32, 34, or whatever, I probably won’t check it again until I do routine blood work. But if it is under 20, I have them come back and check it.

Provider participants often pointed out where they learned about vitamin D and how they kept up to date on the practices and controversies. Providers discussed peers, medical societies and conferences, newsletters, the Internet, and personal experience as sources of knowledge. Several providers mentioned that their awareness or knowledge came from their own experiences with being tested and treated for insufficient vitamin D. For example, one PCP recalled:
And then along the way somebody put some stents in me, and I started checking my cardiac patients for vitamin D. Because I’m an old country boy and I’m in the sun a lot and I shouldn’t have had a deficiency in vitamin D, but I sure did.

Another PCP reported that there were several simultaneous sources of knowledge:

Well, believe it or not, it was actually an endocrinology fellow where I trained at [residency site], who vitamin D was his little thing, and he gave a lecture on it…. You know, he took ginormous amounts every day. And so, and that was right about the time that we were starting to think that it was linked somehow to chronic pain and fatigue and depression and that sort of thing. So that, I think that, that all of those things at once started to, I guess, open up my eyes. And also I think that something in our, somebody at [residency site] was doing like a … review on vitamin D supplementation in kids, too, so it was kind of a number of things all at once.

**Uncertainty**—The second most prevalent, and seemingly contradictory, theme that emerged was uncertainty ($n = 127, 23\%$). Four subthemes categorized what providers were uncertain about in their practices: indicators, testing, treatment, and benefits and risks. One provider discussed indicators that helped to determine when testing was appropriate, but even then felt uncertain about how informative the tests really were:

Well, one thing I am really curious about, what I consistently see in the African American population, and I don’t have a lot of Hispanic, but I do have some Asian, dark skinned Asians. And of course those individuals have a lot lower levels. If I see a five or sjx, it tends to be darker skinned individual. And I would be very curious to see if that is not, the “normal values” are maybe skewed for a more Caucasian, or lighter skinned population, and maybe normal for darker skinned individuals is lower. It may be a problem that we are just not aware of. I don’t think anyone has researched it.

When they tested their patients, providers still expressed uncertainty about what the test results meant. One PCP stated, “So I haven’t sat down to research it. But what is normal? How do they come up with the normal?” Another posed questions about when to test patients: “Is it recommended to do a universal screening? My understanding is that it is for everybody even if they aren’t at any obvious risk.” A third PCP echoed these concerns about technical aspects of testing:

There is also, in my understanding, some controversy surrounding the change in test parameters as well. Such that part of this epidemic of vitamin D deficiency may have something to do with the fact that we just changed what normal is, as much as that everybody is all of a sudden abnormal, if that makes sense.

Another provider articulated a common uncertainty concerning how vitamin D is perceived by patients:

It’s one of those topics that in my mind is kind of in vogue right now, so I’m always worried about my patients hanging their hat on something like vitamin D deficiency as the root cause of their problems such that, if we just top off their vitamin D, that they’re going to feel a whole lot better. Because I can’t honestly tell them that that’s true.

**Provider perception of patient role**—The third theme focused on the perception providers had about their patients’ roles ($n = 116, 21\%$). They perceived that patients fell onto a spectrum, with some patients exhibiting no awareness of vitamin D and others demonstrating practical knowledge. Providers perceived that the patients who played a role
in their own health care had been shaped by other information sources, with specific references to the media and Internet. One noticed a trend in patient awareness, stating, “We are seeing them come in with information, just as I am sure other practitioners are, asking about this.” Conversely, some providers thought that patients had very little awareness about vitamin D: “I was usually initiating it [vitamin D testing]. No one; I can’t remember any family initiating it.” Providers also shared their perception of where patients were getting their information. For example:

I think the information, like information on any health, any sort of health hot topic, is probably 50:50. A lot, most people, are going to the Internet. A lot of the children of our patients are obviously in the baby boomer era and aging themselves and they are very tech savvy. So, most of them are getting their information from the Internet. Other sources our patients get information is from newspaper clippings, or articles in popular magazines.

Responsibility—Not surprisingly, providers acknowledged that they felt responsible for their patients’ health (n = 66, 12%). To fulfill this responsibility, the providers enacted their caregiving role through testing, treatment, and follow-up visits about vitamin D. This responsibility, however, was sometimes overshadowed by the need to tend to other priorities perceived as more significant for the patient’s health. In fact, every provider admitted that vitamin D was not always a priority. One said:

Oh yeah, as far as even talking about it, I think that the problem that most of us have in primary care is that we are dealing with so many things in a short time in a visit, that we don’t always remember to bring it up, and if they don’t bring it up, then it goes to the next time or something.

Another seemed overwhelmed with the number of things that needed to be discussed with any one patient:

I mean it would just be, just one more thing on our list of health issues to talk to them about. So, you know, we are talking to them about so many things as it is. I don’t think it would change much, just be one more thing.

Providers also saw their role as one that included educating patients about their health, including vitamin D. A PCP shared, “We try to, if there is any question, provide resources for them. You know, Internet sources like Web MD or sources that we find more credible, or we’ll do handouts.”

Skepticism—Providers were aware of the controversy surrounding vitamin D and therefore still skeptical about using it (n = 58, 10.5%). Providers expressed skepticism about three areas: the conflicting evidence, lack of recommendations from credible sources, and past experiences with harmful vitamin treatments. One shared:

I think it is confusing. I think there is a lot of information out there. I think it is very difficult to process. I’ve had other physicians tell me that vitamin D testing is stupid and they don’t understand why we have to do it because there is no evidence and it doesn’t really show us anything. My argument is that is not really true, especially when you look at the data in my population [nursing home residents]. I guess my biggest concern is that patients and physicians also are not getting the full picture.

Another pointed out that there was even a lack of consensus within her area of specialization (the pediatric population):
And then, lack of consensus. I think vitamin D is definitely one of those things that people have very strong opinions about. Consensus … even around vitamin D for breast fed babies. You would be amazed at how people … don’t even agree on that.

Providers were also struggling to find credible recommendations. One said, “I think that I would need a stronger position from our national academy … around deficiency and treatment. Right now they are on the fence, but I could be wrong.” Another shared this opinion, but acknowledged that recommendations must be built on consensus and empirical data:

And that is okay if they are reading recommendations from national, reputable sources, but you know, everybody has a bias. It is like PSA [prostate specific antigen] testing, or anything else, everybody has a bias. You know the prostate cancer folks are going to tell you something different from family physicians, and even something different than the NIH folks. So my concern is getting enough information out there to come to some evidence base.

Much of the skepticism that providers faced was attributable to past experiences with testing and treatment, and in some cases related to the side effects associated with other vitamins. One PCP said:

The only thing, you know, it’s like vitamin A…. Vitamin A was big. A, D, E, and K you know are fat-soluble, so I’m always kind of concerned about those because you can get too much of a good thing.

Uncertainty management—Although greater than 40% of the coding units exhibited provider uncertainty, mention of uncertainty management as a specific theme was less common (n = 29, 5%). Providers discussed a variety of information sources they sought to reduce their uncertainty; however, the majority of information seeking was passive. When asked what she did to get more information about vitamin D; for example, one provider said:

Very little…. It is more the newsletters and articles and things like that. So I’ve not read any research articles or spent any time looking into it in depth. So basically my knowledge is based on more the superficial articles that are coming across my desk from our academy.

Another agreed: “We usually review most of the new vitamin D articles that come out in our journal clubs. And that sort of helps keep everybody abreast of what is going on.” When actively seeking information to reduce uncertainty, many providers also used the Internet as a source of information; for example, “Yes, I don’t read many peer articles anymore. The American Academy of Family Practice will have occasionally an article about it … but I just use the Internet now.”

Evolving perceptions—Although providers’ knowledge of vitamin D was relatively current, they also acknowledged that information about vitamin D is rapidly changing, and consequently, they described evolving perceptions (n = 14, 2.5%). When asked how perceptions of vitamin D had changed over time, one said:

It seems to me that most of the research came out since the time I finished residency, so it’s kind of an evolving thing that … I mentioned that it’s on my radar and I try to keep up with it, but I also, I can’t say that I’ve had that many difficult patient questions that I felt I couldn’t answer.

Another also discussed the changing perception of vitamin D: “Over the last couple of years, I guess, it has evolved from thinking it was this wonderful potentially cure all. Everything to my understanding now, being that it is much more specific.”
Community Member Focus Groups

The community member participants (N = 89) were comprised of men (n = 6) and women (n = 83) who ranged in age from 27 to 91 years (M = 60). The participants reported that they were White (n = 65), African American (n = 14), other (n = 2), or did not report race/ethnicity (n = 8). As their highest degree, participants reported having less than a high school diploma (n = 3); a high school diploma (n = 36); college or graduate degree (n = 48); or did not report education (n = 2). We identified five themes with up to nine subthemes each, again listed in order of prevalence. Cohen’s Kappa =.93.

Uncertainty—Uncertainty was the most common theme among the community participants (n = 84 consumer coding units out of 222, or 38%). Participants voiced an overwhelming number of questions to the facilitator or focus group, including such questions as: “Can you get enough vitamin D from regular activities?” “Are there other foods to which vitamin D is added?” “On a daily basis, what is the normal amount of vitamin D you would get?” “If it is fat soluble, is it stored seven days?” “Why do African Americans not absorb vitamin D well?” Expressions of uncertainty, doubt, or even skepticism about the value or potential benefit of raising vitamin D levels were also mentioned a substantial number of times. One person asked, “If you are in the normal range, do people need to be in the higher range? What would be the benefit if I took more vitamin D?” Several of the focus group participants did have uncertainty about treatment and the risk of overdose. A few people were unsure whether they had been tested; one said, “I had a comprehensive blood test a month ago. Would they have tested for that?”

Questions about the relationship of vitamin D to medical conditions were the most common sources of uncertainty. One patient said, “Everyone tells you something different to do; very confusing; don’t know what to do.” Similarly, another expressed frustration and confusion: “You have three doctors and each tells me and gives me different things.” The issue extended beyond just health professional advice, with a number of people also expressing confusion about mixed messages in the media, stating, “Conflicting research. One day it is good for you and the next it is not.”

They also complained that awareness created uncertainty and the media did not provide a way to manage that uncertainty: “Dr. Oz has so much information but never tells you what to do about it. It makes you more aware but the next day he is talking about something else.” One person even recognized provider uncertainty, saying, “Good doctors are very hesitant to let you [the patient] know, because so much research is going on and research can be conflicting.” Participant uncertainty also manifested as lack of confidence in the provider, with comments ranging from, “I don’t trust my doctor’s advice about nutrition,” to, “My doctor doesn’t keep up with current information.” Some expressed only partial trust in the provider, with such statements as, “Yes [I trust my doctor], but I always do my own research afterward so I know,” and, “Yes, but I check WebMD and I am my own doctor in a way.”

Information sources—The second most prevalent theme in the data was information sources (n = 63, 28%). Sources of knowledge for participants included expert advice or recommendations from a personal health care provider, television (e.g., Dr. Oz), commercials for various vitamins and products supplemented with vitamin D, family and friends, the Internet, and print media. One participant’s quote characterized a number of these sources of information:

I have a fracture in foot so doctor gave it to me…. First told me to take it over the counter. I ask many questions. I never asked for four months and the doctor said the level was low but it doesn’t matter. I asked, “What do you mean, it doesn’t matter?” Then I asked, “What is my level?” And he ordered a blood test. I did my
own research and found what it is. I didn’t know what the normal levels were. My specialist said normal level was 40 to 180. She did a lot of research too and discussed it with me.

Awareness/knowledge—Awareness (n = 38, 17%) about vitamin D as a health concern was the third most prevalent theme among the community participants, though there was no consensus on the level of awareness. Many participants had never heard of vitamin D testing or supplementation, and others had been following the controversy through the media. One participant seemed worried by the discussion, stating, “I have never had a concern about vitamin D until today.” A number of participants voiced the perception that most people in their area are not finding out about vitamin D, as epitomized by the comment, “Majority don’t. I knew nothing until I came here. We can look up anything on the Internet, but if we aren’t concerned, we won’t find out.”

Other participants, however, were able to name appropriate doses of prescription or over-the-counter supplements, knew that sunlight, milk, and fish were existing sources of vitamin D, and mentioned bringing up vitamin D or asking to be tested at medical visits. Some even mentioned more complex details of vitamin D management and were confident in their knowledge. One responded to another participant’s question about how much vitamin D is recommended with, “1,000 to 2,000 without a prescription and then based on how low you are. I take gelcaps three times a day.”

Barriers—The fourth theme for community members was barriers (n = 26, 12%) including financial, low interest or priority of vitamin D, concerns about side effects, diets, lack of communication, and distrust. For example, access to appropriate dosages was a concern among a number of people: “They change the label of the vitamins and I can’t find what I am used to getting.” For others, it didn’t seem like a priority. Specifically, one participant stated, “I have been on vitamin D several years…. I take it every week faithfully. I feel I am taking it for nothing because it is never detected…. I feel like I need to do it, but why?” Community participants did express concerns about potential harms of getting too much vitamin D, making comments such as, “I worry about taking too much,” and, “Many people just overdo it by taking vitamins when they don’t need them.” The communication process within the health care system also hindered community members from following up on vitamin D, as expressed by one patient: “You have to ask for test results to be sent to all doctors if you want them to be on the same page.”

Patient-provider relationship—The quality of the relationship between the patient (as represented by our community participants) and provider was the final theme to emerge (n = 11, 5%). Participants expressed notions of complex relationships with providers. Most clearly depended on providers and trusted much of their advice, but also felt that as patients they had to be proactive and responsive to get good medical care. One participant disclosed, “Most doctors will only talk to you about what you are there about. You have to request time and appointments to just talk to them about nutrition and diet.” Another said, “I don’t see the doctor giving everyone the same information…. You are lucky if you get to see a doctor fifteen minutes after waiting.” Another participant recognized different levels of openness and trust with different providers: “We have a good doctor and a great pharmacy that really is good. I pay attention to the pharmacists. My doctor listens and he is really good.”

Discussion

We examined uncertainty about vitamin D and the uncertainty management practiced by two major stakeholders in the conversation: primary care providers and health care
consumers. Using qualitative interviews and focus group interviews, we revealed several themes that illuminate areas of uncertainty and coping mechanisms of those experiencing uncertainty. Specifically, seven primary care providers identified seven major themes: awareness, sources of information, uncertainty, the role of the patient, the role of the provider, uncertainty management, and evolving perceptions. Community focus groups identified five related, but distinct, themes: awareness/knowledge, sources of information, uncertainty, barriers, and the patient-provider relationship. Our research questions concerned the characterization of uncertainty and its management by both the providers and the community. Both the providers and the focus group members contrasted their awareness with their uncertainty as prominent themes. We did not come to the research with a preconceived theory of management, but found through analysis that Brasher’s uncertainty management theory and its variations corresponded to a number of the strategies demonstrated by the participants. These strategies were evident even though the community members did not express uncertainty management as an overt theme, and it was not the most common theme for providers.

This data adds to the literature by examining uncertainty and its management strategies in the setting of a common primary care issue. Although there is limited literature documenting active and interactive strategies to manage uncertainty among patients or the public, most studies are done in the setting of cancer or other conditions in which life or death decisions are being made (Clayton, Dudley, & Musters, 2008; Parascandola, Hawkins, & Danis, 2002; Sung & Regier, 2012). These studies might not represent the more common chronic disease and prevention communication that every provider and patient must negotiate regularly. Similarly, there is literature on uncertainty as a major factor in physician decision making, but most studies focus only on diagnosis, and there are few examples of more global uncertainty management or application of theory (Fackler et al., 2009; Hyman et al., 2012).

One notable exception was an analysis of clinical encounters between providers and women of perimenopausal age surrounding hormone replacement and screening for osteoporosis and breast cancer. These primary care issues are common and similar to vitamin D in the degree of uncertainty and controversy in their application and management. Although Griffiths, Green, & Tsouroufli (2005) did not apply an established theory of uncertainty management, they identified a number of strategies used by providers to cope and communicate. These included using tests to “rule out” less likely diagnoses (what they called “certainty for now” approach), using discussion of statistical risk to craft another strategy they named the “coherent story of certainty,” and making provisional plans when providers chose to acknowledge uncertainty directly.

Their findings corroborated prior evidence that trying to craft a coherent story to approximate certainty was particularly unhelpful to patients. Although their article is very pertinent to the field, it is difficult to directly compare these strategies to our data because the authors did not focus on how the providers managed their own uncertainty, but rather how they communicated it to the patients (Griffiths et al., 2005). Editorialists consistently recommend that physicians, traditionally trained to demonstrate confidence and avoid ambivalence when communicating to patients, actually learn to express uncertainty to facilitate a patient-centered approach to care. There is ample evidence, however, that physician expression of uncertainty is associated with a reduction in patient satisfaction and confidence (e.g., Blanch, Hall, Roter, & Frankel, 2009; Johnson, Levenkron, Suchman, & Manchester, 1988; Ogden et al., 2002). These seeming contradictions and the articles exploring nuances in strategies and communication highlight the complexity associated with uncertainty management and its influence on the success of a “patient-centered” approach.
In our study, both the providers and community members expressed significant uncertainty about vitamin D. These uncertainties affected the ways in which they communicated with one another. In efforts to manage uncertainty, health care consumers actively sought more information about vitamin D from experts, friends and family, the Internet, and other media. Although PCPs wanted their patients to be proactive in their own health care, providers also expressed frustration with patients bringing in beliefs about vitamin D garnered from popular media and Internet sites. Providers nonetheless also admitted that they commonly used the Internet as a primary source of information.

The providers also disclosed multiple affective responses to their own uncertainty. They sought to both decrease and adapt to this uncertainty. They believed that adapting to uncertainty was necessary because research is incomplete and rapidly evolving. Seeking guidelines from professional organizations served as one way to decrease uncertainty. Experts disagree on the interpretation of current research, however, and most of the organizations that providers look to for guidance have not yet developed recommendations. The PCPs felt a strong responsibility to their patients and interpreted that responsibility as a duty to continue seeking information. They employed multiple strategies outlined in uncertainty management research: mostly passive (e.g., receiving information at larger educational conferences or through unsolicited literature); some active (e.g., consulting with colleagues, family and friends, or their own providers); and very limited interactive (e.g., consultation with experts in the field or directed, evidence-based literature reviews). They also practiced some avoidance of information, choosing to remain uncertain, for several reasons. Specifically, the providers reported prioritizing education that they perceived to be more valuable to themselves or their patients. They also recognized that not all vitamin D research was valuable or even legitimate given the mixed results. In summary, a number of providers generally avoided addressing vitamin D with patients because their passive uncertainty management strategies were not adequate to assuage their skepticism, whereas others used active strategies to justify more assertive testing and treatment of their patients.

Although uncertainty management did not emerge as a major theme in the community focus groups, it was woven into the gestalt of the conversations. Most community members did demonstrate attempts to reduce uncertainty through their own information seeking on the Internet, through family and friends, or in the media, sometimes before they had talked to a provider about vitamin D. They also actively searched for more information about vitamin D when they perceived their provider to be uncertain about vitamin D testing and treatment. Despite that “outside” search, the prominent mechanism of uncertainty reduction for the community members was inherently communicative. Specifically, community members reported engaging in active uncertainty reduction by seeking information from friends and family and using interactive approaches through asking providers for more information about vitamin D. Many participants even used the research focus group setting as an opportunity to actively and interactively seek information through asking questions of their peers and the facilitator.

Taken together, it appeared as though providers made assumptions about the knowledge their patients possessed, the patients’ sources of knowledge, and the patients’ barriers to treatment and supplementation. The community health care consumers, who represented typical patients, rarely confirmed these assumptions. The providers, for example, perceived that very few of their own patients had significant awareness of vitamin D and that those who did got all their information from the Internet and the Dr. Oz television show. Conversely, the focus groups revealed that community members generally had a fairly high level of awareness about vitamin D, though many still harbored questions and misconceptions.
Although community members reported passive and active information seeking through health websites and television shows, they more often garnered specific vitamin D knowledge through interactive management when they themselves or a family member was treated by a provider. This communicative disconnect highlights a critical junction for both provider and patient to collaborate on developing a more open and interactive patient-provider relationship that elicits more realistic and accurate views of the knowledge held by the lay community.

Additional evidence of the need for relationship building was represented by the community members’ concerns about potential harms, as well as general distrust in the health care, health insurance and supplement industries. This distrust is clearly related to communication with their health care providers. A number of them believed their doctor was not competent or interested in nutrition topics, was not up-to-date on the latest developments with vitamin D, or did not have enough time to actually discuss questions and concerns they might have about testing and treatment. This pattern seemed to be perceived as part of a systemic health system problem including short patient visits, poor communication between provider and patient, mixed messages, and lack of coordination among providers.

This community-level frustration in accessing quality time with providers and trying to discern the competency of PCPs illustrates that for patients, consulting with a provider is the highest level of uncertainty management: the interactive approach. There is no greater authority to which one can appeal for more or better information than other experts. Providers do not generally consider the interaction with the patient an uncertainty management activity because the patient is not viewed as an expert or source of information or skills. Providers were nevertheless having the same frustration when they looked toward their medical societies and experts in the field and also found little information on which they could rely. Relating their own uncertainty to the patient then reduced their ability to relieve uncertainty for the patient. This finding corroborates other evidence showing that providers experience significant stress concerning their own uncertainty and the difficulty in communicating it appropriately to the patient. (For a relevant article and review, see Bovier and Perneger, 2007.)

Although this phenomenon is common in health care, conceptual models seldom address the interaction of provider uncertainty management, patient or consumer uncertainty management, and related communication in the context of strategies for improvement in outcomes or experience. One avenue to facilitate patient-centered communication is for providers to view the patient as an expert in his or her own experience of care. In a study examining the practices of providers considered experts in “contested illnesses” such as chronic fatigue syndrome, Swoboda (2008) reported that physicians who felt confident in diagnosing an ambiguous illness more often employed “patient-collaboration” as a diagnostic tool than those who did not. In the case of vitamin D management, the provider who views the patient as the authority on the cost, tolerability, and manner of supplementation could potentially have a more productive conversation in which both parties could reveal uncertainties without loss of confidence. Additionally, Niland and Lyons (2011) suggest that medical educators emphasize uncertainty as opportunity for discovery and exploration for providers, a stance that theoretically complements the process of appreciation for accepting the expertise that the patient brings to the encounter.

Although our study is strong because of the theory driven nature of the analysis and the in-depth data collected from multiple viewpoints, there are also limitations. First, the number of provider participants was relatively small, and we were not able to recruit nurse practitioners or physician assistants. Additionally, two of the providers focused on geriatric and pediatric populations, respectively, raising the question of whether vitamin D was
equally relevant to all providers. These concerns were mitigated because vitamin D deficiency is common across age ranges, the seven physicians represented a variety of experience levels and practice settings, and the providers converged on a common set of themes. Nonetheless, we recruited only primary care providers, and their views should not be generalized to providers in other specialties.

Second, we did not match the community members to their own providers, but rather chose members of community groups to represent people who would be typical primary care patients. Three of the providers did practice in the same county represented by two of the focus groups. Third, the community member sample was predominantly made up of well-educated women. Selection bias is inherent in convenience sampling, with both provider and community participants more likely to have interest or experience with vitamin D than non-participants. Future researchers should recruit additional providers and their current patients for matched dyadic data collection and analyses. Furthermore, researchers should apply uncertainty management theory frameworks to other medical contexts to improve understanding of the daily health decisions of typical lifestyle and health behaviors instead of only the contexts in which potentially terminal illnesses are the communicative focus.

Conclusion

Uncertainty surrounding the evolving knowledge of vitamin D deficiency and other similar conditions will not dissipate in the near future. Effective management of uncertainty, although a challenge, is a potential coping mechanism for providers and patients. Our results suggest that providers underestimate patient willingness to learn about and supplement vitamin D, and they might overestimate logistical barriers. They often fail, however, to account for the major barrier: patients’ perception that they do not have access to clear communication. Community participants’ ability to understand the limitations of vitamin D research also suggests that more effective patient education might be elicited through an interactive approach. Interactive patient-provider communication occurs when both parties view the other as expert in certain elements of treatment, disclose their own uncertainty, and negotiate a management plan. Their goal is to both adapt to and cope with that uncertainty simultaneously. In other words, despite the choices available to an uncertain individual, patient-provider communication remains the central component to management.

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Appendix A

Provider Interview Guide

Please comment on your own level of awareness of research and current practices concerning vitamin D.

If does feel moderately or well aware:

What first made you aware of vitamin D as a health topic?
Do you have a sense of whether you think it is important as a health topic?
What has been frustrating about trying to understand vitamin D as a health topic?
How do you usually become aware of information that eventually changes something about the way you practice?
What sources do you typically use for keeping up-to-date with clinical information?
Do these sources differ for different kinds of topics and treatments?
Have you recently changed your practice with regard to vitamin D testing or treatment?
Why or why not?
If so, how?
What questions or concerns do you have regarding vitamin D testing and treatment?

If does not feel very aware:

What have you heard about vitamin D research and practice lately?
What sources have been your primary ways of hearing this?
Do you have a sense of whether you think it is important as a health topic?
What has prevented you from being able to find out more about vitamin D as a health topic?
How do you usually become aware of information that eventually changes something about the way you practice?

Have you recently changed your practice with regard to vitamin D testing or treatment?
Why or why not?
If so, how?

For all

If not covered by the above conversation:

Do you find that patients approach you concerning vitamin D?

How do you advise patients concerning getting enough vitamin D?

If you recommend over-the-counter supplements, how much?

Do you test for vitamin D levels?

If so, routinely, or only in certain situations (describe)?

How do you decide when to treat?

How do you usually treat vitamin D deficiency/insufficiency?

Based on what you’ve read or heard, do you think it is important to improve vitamin D levels or number of people with “sufficient” levels in the general population?

What do you think are the most important barriers preventing more people from becoming sufficient in Vitamin D?

What are the best ways to achieve vitamin D sufficiency in more of the population?

Non-priority issues to direct conversation to if time:

Is your current understanding of vitamin D similar or different than what you learned in school or training?

Do you think you understand how to manage vitamin D in some populations better than others (for example, the elderly, children, pregnant women, people with certain health conditions)? If so, please describe.

Why do you think there is or isn’t a difference in knowledge and awareness for different populations of patients?

What do you know about the cost of vitamin D supplementation?

If you have brought up the topic of vitamin D to patients in the form of counseling, testing, or treating, what have been the general responses of your patients?

Appendix B

Focus Group Facilitator Guide

What have you heard about vitamin D?

If there seems to be little to no awareness of vitamin D among some members of the group, possible prompts include:

Memories of being given cod-liver oil which is a rich source of vitamin D

Awareness of the disease of rickets; perhaps knowing a child who had this
Hearing conflicting information on how much time people should spend in the sun and whether they should wear strong sunscreen

If the following sources do not come up in conversation, direct toward:

Where did you hear or read this?

Do you recall seeing reports about vitamin D on TV or radio, or in newspapers or magazines?

Do you recall finding information about vitamin D on the Internet?

Do you trust the information you find in the media or your sources on the Internet?

Has a healthcare provider or someone who works in a hospital, doctor’s office, or pharmacy ever talked with you about vitamin D? If so, who?

Do you trust your doctor or healthcare provider to be able to give you good advice on vitamins and nutrition?

If your doctor or nurse practitioner has not talked to you about vitamin D, why do you think he or she might not have?

What about family or friends? Have you talked with them about vitamin D or about taking vitamins in general?

Do you find it difficult or easy to find information about whether or not to take vitamins? What makes it difficult or easy, specifically?

What have you heard and read are the benefits or good things that come from getting enough vitamin D?

What have you heard and read are the risks or dangers of too much vitamin D?

Would taking extra vitamin D worry or concern you?

Why or why not?

Non-priority issues to direct conversation to if time:

What do you know or what have you heard about where the vitamin D in our bodies comes from?

Based on what you’ve heard or read, who do you think should take a vitamin D supplement?

Who should not?

What amount should the average person get every day?

Do you think children should take vitamin D?

What would be the most likely reason you would start taking a vitamin D supplement?

What would be the most likely reason you would not take a vitamin D supplement?

If you knew that taking enough vitamin D would help your bones and lower your risk for colon cancer, how much would you be willing to pay each month to take a supplement?