

Patient experience and use of probiotics in community-based health care settings

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Objective: To investigate patient experience with probiotics and factors that influence probiotic use among adult patients.

Method: Patients were invited to complete a questionnaire that assessed their experiences and opinions regarding probiotics. Questionnaires were distributed to patients seeking primary health care services at a family and community medicine practice site and a community pharmacy. Patients were invited to complete the questionnaire while awaiting the physician or waiting for prescriptions to be filled.

Results: Overall, 162 surveys were completed and returned (66% response rate) from patients aged 18 to 89 years of age (mean 49.5 years). Most patients (n=107; 65%) were familiar with the term “probiotic”, and 49 patients (29.9%) had personally used the supplements in the past. Of those who had used probiotics, the majority (57%) had used the supplements to maintain “good gastrointestinal health” and most (59%) felt that the supplements had been beneficial. However, most (59%) had not informed their health care provider about their use of the supplements.

Conclusion: Use of probiotic supplements is common among consumers, but may not be reported to health care providers.

Keywords: primary care, community pharmacy, probiotic

Introduction

Probiotics are defined by the Food and Agriculture Organization of the United Nations and World Health Organization as “live microorganisms that, when administered in adequate amounts, confer a health benefit on the host”.¹ Currently considered in the realm of complementary and alternative medicine (CAM), these bacterial therapies are purported to be efficacious in treating a wide range of gastrointestinal issues and helpful in maintaining a healthful balance of intestinal organisms.¹ In the USA, probiotics are regulated as foods or food supplements and are widely available to consumers.

In contrast to marketing for prescription medications, promotion of probiotics is loosely monitored by the US Food and Drug Administration. Unlike the information that must be conveyed to consumers with prescription medications, almost half of probiotic-related websites do not mention risks associated with probiotic use.^{2,3} Furthermore, regulations currently do not require probiotic manufacturers to demonstrate efficacy for health claims.⁴ Incomplete or misleading information is common, and websites run by commercial entities provide consistently less accurate data than those of a non-commercial nature.³

At a recent probiotic conference, it was reported that global sales of probiotics are expected to rise 48% – from \$2.7 billion in 2011 to \$4 billion in 2016. The strongest growth worldwide is in the USA; new sales of \$140 million were reported in the USA in 2011 alone.⁵ Furthermore, according to conference participants, consumers are interested

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in the addition of probiotics to “normal” food products that are consumed daily and “support digestive health”.⁵

A number of factors may impact probiotic efficacy. First, not all strains of bacteria marketed as probiotics have the same effects. Current evidence suggests that even different strains within the same species differ in their activities.⁴ Current regulations in the USA do not mandate probiotic labeling to indicate strain designations. Additionally, quality assurance testing (viable cell counts, shelf-life, and appropriate storage conditions) is left to the discretion of individual manufacturers. Thus, probiotic quality and efficacy vary considerably.

While most research is directed toward understanding the mechanisms by which probiotics exert their effects, little data exist regarding the factors that influence patients to consume probiotics or what they expect of these products. Given the common use of these supplements, we wished to identify the characteristics of individuals who use probiotics as well as assess their experiences and opinions regarding probiotics through use of a questionnaire.

Methods

Patient identification and recruitment

Patients were recruited from a family and community medicine practice and a community pharmacy. Using a computer-generated, random number table, individuals from 18 to 90 years of age were invited to complete a questionnaire while waiting for a physician visit in the medical office or for prescriptions to be filled at the pharmacy.

Questionnaire

The questionnaire was a branching instrument that included ten demographic questions (sex, age, education level, income) and also solicited input regarding probiotic familiarity, use, and opinions. The questionnaire was pilot tested for content validity in a small group of health care consumers. Individuals who had previously used probiotics were directed to answer 18 related questions, whereas those who had not used probiotics answered 12 different questions (Figure S1). All questionnaires were completed anonymously, and individual responses were not linked to specific patients. Patients were able to skip questions they did not wish to answer. This study was approved by the Investigational Review Board of the Milton S Hershey Medical Center.

Statistical analysis

Descriptive data including means and standard deviations were calculated from responses to the questionnaire. The χ^2

test was used for comparisons between groups. All data analysis was conducted using JMP 8 (SAS Institute Inc., Cary, NC, USA).

Results

A total of 249 surveys were distributed (physician office – 50; pharmacy – 199), and 166 surveys were returned (physician office – 45; pharmacy – 121). Of these, two surveys were not included in the study; one returned survey was left blank, and one patient did not meet the inclusion criteria (age >90).

Participants’ ages ranged from 18 to 89 with a mean age of 49.5 years. Most (n=99, 60.4%) participants were female and the majority (n=145, 88.4%) self-identified as Caucasian (Table 1). The most common education level was “High School/GED” (n=42, 25.6%), and the most common annual income level was between \$25,000 and \$49,999 (n=32, 19.5%).

Table 1 Demographics of population

| Characteristic | n (%)* |
|---------------------------------------|--------------|
| Age, year, mean (range) | 49.5 (18–89) |
| Female | 99 (60.4) |
| Ethnicity | |
| African/African American | 3 (1.8) |
| Alaskan native | 0 |
| American Indian | 0 |
| Asian/Asian American | 1 (0.6) |
| Caucasian | 145 (88.4) |
| Latino | 3 (1.8) |
| Native Hawaiian/Pacific Islander | 0 |
| Biracial | 1 (0.6) |
| Other | 2 (1.2) |
| Do not wish to answer | 9 (5.5) |
| Education level | |
| High school diploma/GED | 42 (25.6) |
| One or more years of training/college | 28 (17.1) |
| Associate’s degree | 29 (17.7) |
| Bachelor’s degree | 29 (17.7) |
| Master’s degree | 21 (12.8) |
| Doctorate or professional degree | 11 (6.7) |
| Do not wish to answer | 4 (2.4) |
| Income range, annual (USD) | |
| <25,000 | 16 (9.8) |
| 25,000–49,999 | 33 (20.1) |
| 50,000–74,999 | 30 (18.3) |
| 75,000–99,999 | 26 (15.9) |
| 100,000–150,000 | 19 (11.6) |
| > 150,000 | 13 (7.9) |
| Do not wish to answer | 27 (16.5) |

Notes: *Data are represented as numbers of patients with percentages given in parentheses, except age which is denoted by mean (range).

Abbreviation: GED general educational development.

Probiotic knowledge and experiences

The majority of respondents ($n=107$, 65.2%) rated themselves as being “familiar” with probiotics to some extent, although 54 (32.9%) participants had not heard the term previously. Of those patients with some knowledge of probiotics, the most common source of their information was TV or radio (31 of 164; 18.9%). A minority of respondents (49 of 164; 29.9%) had personally used probiotics. Of those who had tried probiotics, most ($n=39$, 79.6%) had consumed them as a food product as opposed to a capsule/pill/powder. *Lactobacillus* was the most common bacterial strain that participants could identify by name (12 of 49; 24.5%); however, a number of respondents ($n=19$, 38.8%) who had used probiotics previously were unable to identify the bacterial strain in the product they had used. No statistically significant differences were identified between use of probiotics and income level, age, sex, ethnicity, or education level.

Perception of probiotic treatment

Of the 49 patients who had tried probiotics in the past, 29 (59.2%) individuals felt that they received some benefit from the supplement, a single individual (2.0%) believed that no benefit was conferred, and the remainder of patients ($n=19$) were unsure. The most common reasons for probiotic use included: maintenance of good gastrointestinal health (28 of 49 prior probiotic users, 57.1%), benefits on the immune system (20 of 49 prior users, 40.8%), avoidance of medication side effects ($n=13$ of 49 respondents, 26.5%), and positive experiences with the supplements by others ($n=12$ of 49 respondents, 24.5%).

The majority of patients who had never taken probiotics would be willing to try the supplements (74 of 102 responses, 72.5%). Potential side effects and questions about the effectiveness of probiotic treatments were the two most commonly cited concerns of those who had never used probiotics ($n=67$ of 102 responses, 65.7%).

Communication about probiotics

When respondents who had previously utilized probiotics ($n=49$) were asked who had recommended that they try the supplements, participants were permitted to choose more than one response. Recommendation by a friend ($n=13$, 26.5%) was the most common response, followed by suggestion of a physician ($n=11$, 22.4%) or a family member ($n=10$, 20.4%). Media (television or radio advertisements) was also cited by five respondents (10.2%).

Of those patients who had used probiotics before ($n=49$), a majority ($n=29$, 59.2%) had not informed their

health care provider. The most commonly cited reason was that the patient “did not think it was important” ($n=17$ of 29, 58.6%). Of the patients who had informed their health care provider that they were using probiotics, the majority (14 of 19 responses) indicated that their provider had responded positively.

Preferences regarding probiotics

If patients were to use probiotics, the majority of survey respondents would like them to be available in food products ($n=88$, 53.6%) or a capsule/tablet ($n=76$, 46.3%). A number of respondents (49 of 164, 29.9%) would be willing to spend as much as \$0.50 per dose, but all respondents were unwilling to spend more than \$1.00 per dose. Furthermore, 21 individuals (13%) indicated that they would never be willing to spend money on probiotics. Of all survey respondents, most would prefer to buy probiotics at a pharmacy ($n=87$, 53.0%), followed by a grocery store (42.1%, $n=69$). To learn more about probiotics, the majority of respondents would first turn to their physician (49 of 80 respondents, 61.3%), followed by a pharmacist (41 of 80 responses, 51.3%), and then the Internet as a third source of information (20 of 80 responses, 25%).

Discussion

In less than 2 decades, consumer knowledge of probiotics in the USA has changed considerably. In 1998, focus groups that assessed consumer familiarity with lactobacilli, bifidobacteria or even the general concept of cultures in yogurt varied from consumers being “knowledgeable” to completely “unaware” and even “repulsed” at the thought of eating bacteria.⁶ In contrast, results from our questionnaire indicate that 65% of health care consumers consider themselves “familiar” with the term. This seems to be consistent with results from an online survey of 1,000 US adults conducted in 2011 by the International Food Information Council which found that 65% of respondents were aware that probiotics may be good for the digestive system.⁷

A total of 249 health care consumers were invited to participate in our probiotic questionnaire; 164 questionnaires were completed, returned, and in accordance with eligibility criteria, thus leading to an overall response rate of 66%. This robust response may have been due to completion of the surveys during “free time” while otherwise waiting for a prescription to be filled or to see a physician.

Almost one-third (29.9%) of all survey respondents had tried probiotics in the past; this is similar to the rate reported by a New Zealand cohort (25%).⁸ However, unlike

the New Zealand study which identified a positive correlation between female sex, younger age, and higher education levels and the use of probiotics, we did not find any correlation between these demographic variables and probiotic use. This may be due to our sample size comprised of a relatively homogeneous middle-class population. Also, consistent with a study by Mercer et al our data indicate that patients want their health care providers to be knowledgeable about probiotics, with physicians and pharmacists being the top two choices from which patients desire further information.⁹

In agreement with Schultz et al a number of survey respondents who reported using probiotics previously perceived that they had experienced some benefit from the therapy.⁸ However, the majority (57.1%) of patients who reported having used probiotics previously had done so to maintain good gastrointestinal health. In these cases normal bowel function could have been perceived as an indication of efficacy, with the possibility that patients may have been skewed toward believing a benefit was conferred simply if no untoward effects occurred.

In the present study, patients who had familiarity with probiotics most often indicated that they had first heard of them through the media which is similar to the findings of Mercer et al.⁹ However it is notable that users did not typically cite these advertisements as their primary reason for initiating probiotics; instead most patients began taking them due to a personal recommendation from a family member, friend, or physician who described a positive outcome. It seems that our participants favor anecdotal evidence from those people they personally know over commercial messages. This is consistent with findings by Gerasimidis et al in that patients will frequently use CAM at the recommendation of a friend.¹⁰

There are potential challenges identified in this survey. Although most (61.3%) respondents would like to go to their physician as a primary source for further information about probiotics, the majority (59.2%) of those who had used probiotics did not inform their physician. Most (58.6%) patients who did not tell their physician simply did not think it was important. This seems to confirm the finding of others that patients view probiotics as supplements that can only help and not harm, as opposed to drugs with potential risks.⁹ However, because patients in our cohort would prefer to buy probiotics from a pharmacy (53.0%) or at a grocery store (42.1%), and since 65.7% of them were concerned about side effects, knowledge of potential risks associated with dietary supplements, including probiotics, may be increasing. Additionally, since our respondents indicated a preference

for purchasing probiotics at a pharmacy compared to a supermarket, there may be a preference among our cohort to “take a pill” rather than obtain probiotics through diet. This view from US health care consumers may be in contrast to other international views where probiotics may be more likely to be considered as a component of functional foods like fermented milk products, yogurts, and kefir.^{11–16} However, it is not uncommon for consumers worldwide to have misguided views about the types of foods that actually contain probiotics, as supermarket shoppers in the Netherlands and Brazil believed that cheese, fruits, coconut water, and soft drinks contain probiotics.^{13,17}

The cost of probiotics to consumers is important to consider; respondents to our questionnaire uniformly indicated an unwillingness to spend more than \$1 per dose. An assessment of over-the-counter probiotic products sold at the community pharmacy where the questionnaire was distributed identified eleven products containing various combinations of lactobacilli, bifidobacteria, or *Saccharomyces boulardii* priced at between \$0.32 to \$1.07 per dose. However, among these products, there are substantial differences in composition (probiotic bacteria versus bacterial strains used only for making yogurt), total cell counts (ranging from counts not even stated on product packaging to more than 15 billion organisms per dose), and differing storage conditions (room temperature versus refrigeration) all of which have the potential to impact probiotic efficacy.

Nearly a fifth of our participants stated their preference to gain information online. Health care providers must be willing to communicate with patients that web-based sources of information about dietary supplements are not always accurate.¹⁸ Notably, no patients who disclosed probiotic use to their health care provider had received a negative response. In fact, the majority (68.4%) of patients who had discussed probiotic use with their physician had received a positive response. This contrasts with data from Gerasimidis et al in which 13% of CAM users received a negative response from a health care provider and only 50% of users received a positive response upon informing their physician.¹⁰ While this discrepancy may be in part due to a negative reaction to other types of CAM besides probiotics, it may also suggest that probiotics are gaining acceptance as legitimate adjunctive treatments.

Despite having a good response rate to our survey, a major limitation to this study is the small and homogeneous group of individuals from a community in central Pennsylvania that we were able to reach. Compared to the overall US population, our respondents were comprised of: slightly more female

patients (60% versus 51% nationally), a greater percentage of Caucasian individuals (88% versus 83% in Pennsylvania and 78% nationally), and slightly older individuals (mean age 50 years versus 37 years nationally). However, the educational level of our respondents was consistent with that observed nationally (eg, 29% had a Bachelor's degree versus 29% nationally).¹⁹ Thus, our findings describing patient knowledge and experiences with probiotics may not be generalizable to a younger patient cohort, a more diverse ethnic population, or even individuals with specific comorbidities. Indeed, Hedin et al found that patients with inflammatory bowel disease are more likely to use probiotics, use them several times per day, and discuss probiotic use with a health care professional compared to a control population.²⁰ In an effort to maintain confidential responses from patients, we did not ask about co-existing health conditions, thus we cannot ascertain whether those who reported past probiotic utilization have been given a specific diagnosis for which probiotics could be beneficial.

Conclusion

Overall, we found that use of probiotics is fairly common, that most patients are familiar with the concept of probiotics, and that patients would like their health care providers to be knowledgeable about this treatment option. However, as patients frequently do not disclose probiotic use to their health care provider, physicians and other health care providers may need to take the initiative to be knowledgeable, to inquire about, and to discuss dietary supplement use with patients, so patients will be aware of both potential benefits and risks.

Disclosure

The authors report no conflicts of interest in this work.

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Supplementary material

Figure S1 Questionnaire on patient knowledge and use of probiotics.

1. What is your sex?
 - 1 Male
 - 2 Female
 2. What is your age? _____ years old
 3. What is your ethnicity?
 - 1 African/African-American
 - 2 Alaskan Native
 - 3 American Indian
 - 4 Asian/Pacific Islander
 - 5 Caucasian
 - 6 Hispanic
 - 7 Bi-racial
 - 8 Other: _____
 - 9 Do not wish to answer
 4. How many people live in your household?
 - 1 1
 - 2 2
 - 3 3
 - 4 4
 - 5 5
 - 6 Greater than 6
 5. What is the highest level of education in your household?
 - 1 High school diploma/GED
 - 2 Certificate from a college
 - 3 Associate's Degree
 - 4 Bachelor's Degree
 - 5 Master's Degree
 - 6 Doctorate or Professional Degree
 6. What is your estimated household income?
 - 1 Less than \$25,000
 - 2 \$25,000–\$49,999
 - 3 \$50,000–\$74,999
 - 4 \$75,000–\$99,999
 - 5 \$100,000–\$150,000
 - 6 Greater than \$150,000
 - 7 Do not wish to answer
 7. What is your occupation? _____
- Now we would like to learn about your knowledge and experience with probiotics.**
8. How familiar are you with the word “probiotic”?
 - 1 Extremely familiar – know what the term means, what probiotics are used for and comfortable explaining to other people
 - 2 Very familiar – know what the term means and what probiotics are used for
 - 3 Familiar – know what the term means
 - 4 Somewhat familiar – heard of the term before
 - 5 Never heard of it before (*if you select this answer, go to question #20*)
 9. How did you learn about probiotics? *Check all that apply.*
 - 1 Doctor
 - 2 Pharmacist
 - 3 Nurse
 - 4 Family member
 - 5 Friend
 - 6 Pamphlet
 - 7 Internet
 - 8 TV or Radio news
 - 9 Advertisement on TV or radio
 - 10 Book
 - 11 Clinical Trial
 - 12 Newspaper
 10. Have you ever used a probiotic food or supplement to obtain healthful benefits?
 - 1 Yes
 - 2 No (*if answer, go to question #20*)
 11. Was the probiotic used as a food or a supplement?
 - 1 Food
 - 2 Supplement
 - 3 Both
 12. What organisms are/were in the probiotic you took?
 - 1 Yeast (ie, *Saccharomyces*)
 - 2 Bacteria – *Lactobacillus*
 - 3 Bacteria – *Bifidobacteria*
 - 4 Bacteria – *Bacillus*
 - 5 Mixed bacterial species
 - 6 Mixed bacteria and yeast
 - 7 Do not know
 13. Who or what made you want to try probiotics? *Please pick the answer that best fits your opinion or you may write in your own response in ‘other.’*
 - 1 Physician
 - 2 Pharmacist
 - 3 Nurse
 - 4 Family member
 - 5 Friend
 - 6 Health-food store clerk
 - 7 Alternative care provider or clinic (ie, Naturopath, chiropractor, etc.)
 - 8 Magazine or book

- 9 [] Internet
 10 [] Advertisement on TV or radio
 11 [] Other: _____
14. For what medical condition(s) do/did you take probiotics?
 1 [] Antibiotic-associated side effects (diarrhea, abdominal discomfort, gas, yeast infection)
 2 [] Chronic diarrhea
 3 [] Chronic constipation
 4 [] Inflammatory bowel disease
 5 [] Irritable bowel syndrome
 6 [] Allergic skin conditions (ie, eczema)
 7 [] Prevent recurrence of vaginal infection (yeast or bacterial vaginitis)
 8 [] Maintain good gastrointestinal health
 9 [] Benefits of the immune system
 10 [] Other: _____
15. What was your reason for initially trying probiotics?
 1 [] Dissatisfaction with standard medications
 2 [] Attempt to avoid side effects of standard medications
 3 [] Desperation to do something and feel in control
 4 [] Positive experiences by others
 5 [] Lack of other alternatives
 6 [] To complement other therapies
 7 [] Other: _____
16. Were probiotics beneficial to you?
 1 [] Yes
 2 [] No
 3 [] Not sure
17. Does your physician know you take or have taken probiotics?
 1 [] Yes (*if answer, go to question #19*)
 2 [] No
18. Why does your physician not know about your current or past use of probiotics?
 1 [] Forgot to tell my physician
 2 [] Afraid I would be reprimanded by my physician
 3 [] Did not think it was important
 4 [] It was none of my physician's business
Go to question #22
19. How did your physician respond?
 1 [] Positively
 2 [] Negatively
 3 [] Neutrally
- 4 [] Could not tell
Go to question #22
Answer questions #20–21 only if you have not taken probiotics before.
For your reference, the definition of “probiotics” that we will be using is: “live microorganisms, that when ingested, produce health benefits.” Please keep this definition in mind when you answer the following questions.
20. Knowing what probiotics are, would you ever consider using them in the future?
 1 [] Yes
 2 [] No
21. Major concerns that I have about probiotics include.
Check all that apply.
 1 [] Cost
 2 [] Side effects
 3 [] Effectiveness
 4 [] Attitude of health care professionals towards the therapy
 5 [] Other: _____
- Finally, we want to know about your opinions on probiotics and their use.**
22. If you were to use probiotics, which formulations would you prefer?
 1 [] Incorporated into food (ie, yogurt)
 2 [] Capsule or tablet
 3 [] Liquid
 4 [] Powder
23. If you were to buy probiotics, how much would you be willing to pay for these products?
 1 [] \$0.25/dose
 2 [] \$0.50/dose
 3 [] \$0.75/dose
 4 [] \$1.00/dose
 5 [] More than \$1.00/dose
 6 [] I would never pay to use a probiotic
24. If you were to buy probiotics, please pick the area where you would like to buy these products?
 1 [] Pharmacy
 2 [] Doctor's office
 3 [] Grocery store
 4 [] Health food store
 5 [] Internet
 6 [] Other: _____
- For questions #25–27, please rate the following scenarios on probiotics.*

If I was prescribed antibiotics...

25. ...I would be willing to take probiotics starting from the beginning of the antibiotic treatment up to 4 weeks.
 1 [] Strongly disagree 2 [] Disagree
 3 [] Neutral 4 [] Agree 5 [] Strongly agree
26. ...I would be willing to take probiotics starting from the beginning of the antibiotic treatment up to 2 weeks.
 1 [] Strongly disagree 2 [] Disagree
 3 [] Neutral 4 [] Agree 5 [] Strongly agree
27. ...I would be willing to take probiotics starting from the beginning of the antibiotic treatment only up until the antibiotic treatment ends.
 1 [] Strongly disagree 2 [] Disagree
 3 [] Neutral 4 [] Agree 5 [] Strongly agree

28. Where would you go to learn more about probiotics?
Please rank your answer with 1 being the first option you would use to 5 (or 6 if you include other) being your last option.
- 1 [] Doctor
 2 [] Pharmacist
 3 [] Internet
 4 [] Family or friend
 5 [] Alternative health care provider or clinic
 6 [] Other: _____
 7 [] Not interested in learning more

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