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*J Hum Lact* 2009; 25: 211
DOI: 10.1177/0890334409333422

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Qualitative Analysis of Cancer Patients’ Experiences Using Donated Human Milk

Susanne M. Rough, MS, RD, Pauline Sakamoto, MS, PHN, RN, Caroline H. Fee, MA, and Clarie B. Hollenbeck, PhD

Abstract

This represents the first published account from the patient’s perspective of the use of human milk as cancer therapy. Purposive sampling was used to select a sample of 10 participants. Five were patients and 5 were family proxies. Individual interviews were conducted using confirmatory interviewing technique to obtain individual perspectives on the motivation for cancer patients to take donated human milk. Human milk therapy improved the quality of life (QOL) measures in the physical, psychological, and spiritual domains for most patients interviewed. The patients continued their use of human milk despite cost, taste, and discouragement from the conventional medical community. The study results support the theory that QOL may be more important to cancer patients than cancer outcomes and may improve patient medical care overall. These interviews offer information to cancer patients, their practitioners, and donor milk banks on outcomes and symptom relief from this therapy. J Hum Lact. 25(2):211-219

Keywords: cancer, human milk, donor milk banking, research, quality of life

Research supports that human milk provides not only a superior food for human infants but protective factors as well. While investigating the effect of human milk on bacterial adherence to a human lung cancer cell line at Lund University in Sweden, Hakansson et al1 made the serendipitous discovery that in vitro, human milk causes apoptosis, or programmed cell death, in several varieties of cancer cells. A few human in vivo research studies using a modified human milk protein complex realized similar effects on human cancer cells.2,3 (Human skin papilloma cells were studied in 1 case. Although human skin papilloma infections are usually benign, they may be premalignant.) Because of this knowledge, some people with cancer are requesting human milk. Between 1999 and the present, cancer patients have requested donor human milk from the San Jose Mother’s Milk Bank (SJMMB) as a complement or alternative to their conventional biomedical cancer treatment. However, no information has been collected from these patients regarding their experience with the human milk therapy.

Cancer trials generally measure tumor response, overall survival, toxicity, and level of disease-free status. Complementary and alternative medicine (CAM) is most often used for conditions such as cancer for which no complete cure is offered by conventional medicine. When patients consider CAM, they are...
usually seeking quality of life even when a clinical cure is not expected. The purpose of the present qualitative study is to interview cancer patients who have taken human milk as part of their therapy, to determine their motivation for using human milk, to learn about the effect donor milk had on their quality of life, and to observe how taking donor milk fits into their overall treatment plan. We also asked about their use of other CAM therapies and their communication with their health care team regarding human milk therapy.

Methods

Research Subjects, Sampling, Setting

Because the goal of this study was description and exploration of human milk as a therapy for cancer, purposive sampling\(^4\) was used to access subjects or their family members who were able and willing to describe their experience with human milk therapy. Subjects were limited to cancer patients, aged 18 to 80 years, who had requested and were receiving donor milk from SJMMB from 1999 through 2005. Thirty-nine patients who received donor milk were contacted by US mail and asked to participate. Four letters were undeliverable, 1 patient refused to participate, and 23 did not respond to the request. All 23 were contacted again by mail with no new responses. Of the 11 recipients or family members who responded with signed consent forms, 1 became too ill to continue the study, leaving a final total of 10 participants from the SJMMB.

Personal interviews were conducted between the primary researcher and the human milk recipients. If the recipient was no longer alive, interviews were conducted with a family member or primary caregiver as proxy. Each interview lasted approximately 1 to 1.5 hours. One interview was conducted with each participant. If a person-to-person interview was not feasible, an interview was conducted by phone. All responses were included in the study analysis.

Instrument Design

No gold standard exists for quality of life (QOL) testing. Standard generic, general cancer-specific, and site-specific instruments were evaluated, but none were appropriate for human milk therapy administered to a diverse cancer population. The structured interview is useful when no previous data have been collected regarding a specific therapy, and it was thought to be the most appropriate data collection method for this study. A unique instrument specific to human milk therapy was developed to focus the interview and to ensure consistency between interviews.

Instruments are organized into scales\(^5\) that measure a different aspect or domain of health-related QOL. Lindley\(^6\) reported that the QOL domains most influenced in patients with cancer are symptoms and side effects, social functioning, physical functioning, and psychological status. Economic factors and spirituality are often included. For this study, the investigators sought a multidimensional assessment by including the psychological, social, and physical domains. Prompting questions in the psychological domain included the effectiveness of the human milk treatments as perceived by the patient. Social domain questions assessed the patient’s communication with health care providers, perceived barriers to use of this treatment, cost for the milk, duration and dose of human milk treatment, and sources for locating information on human milk therapy. Physical domain questions assessed the patient’s symptoms before, during, and after taking the human milk therapy and the patient’s response to all therapies. Demographic information was gathered for comparison to other health-related QOL measures, and the patient’s stage and type of cancer before, during, and after human milk therapy were recorded from patient recall. The instrument was limited to 24 questions to avoid fatiguing the participant before completion.

The instrument was pilot tested before use with 3 cancer patients not participating in the study, 2 health care providers, 2 donor milk bank directors, and 2 nutritional science professors. Feedback from the group was used to revise the questionnaire.

Research Procedures

The initial interview question was broadly phrased to allow the patients to identify what they considered important about their cancer and treatment choices. Each participant was encouraged to explain his or her motivation for requesting human milk as CAM. The content and direction of the interviews were determined by the participant’s responses, but a consistency among all interviews was established and maintained by a standard set of prompting questions. Although a combination of note taking and tape recording was used to record participants’ responses, the researchers relied most on extensive notes taken during the interviews. Confirmatory interviewing technique\(^6\) was used. At relevant points throughout each interview, the interviewer read a summary of the participant’s key
concepts to determine whether the notes accurately reflected the participant’s experiences and to see whether the participant wanted to make any additional points or changes. In this way, the interviewer could clarify unclear areas without biasing the participants’ answers. The interviews did not seek to prove or disprove a set theory. The questionnaire and the data collection protocol were approved by the San Jose State University Institutional Review Board for use of human subjects.

Analysis Method

Categories were defined for reporting results, and relevant themes were combined. Data were analyzed descriptively and are presented using frequency, median, and range. Nonnumerical data were analyzed conceptually by the primary researcher, who analyzed the themes and content and identified core concepts from the responses. Ten responses for each of the 24 questions were recorded and analyzed for trends and core concepts. Similar responses were tallied for each question, and personal comments or differences that did not fit a pattern were maintained in the narrative format. When responses overlapped more than 1 category, they were included in the most relevant category.

Results

Participants’ Characteristics

Of the 39 recipients of donor human milk, 11 recipients or proxies agreed to participate, but 1 relapsed before the interview took place and the patient declined to be interviewed. Five of the 10 respondents were patients who answered the interview on their own behalf, whereas 5 of the 10 were family or friends answering for a deceased recipient. Participants were equally divided between male and female and ranged in age from 44 to 86 years with a mean age of 65.7 years. All participants received some higher education, and half were postgraduates. Eight participants were Caucasian, 1 was Asian, and 1 was Middle Eastern. The primary cancer was lung (n = 4), followed by breast (n = 2), prostate (n = 2), colon (n = 1), and lymphoma (n = 1) (Table 1). Patients’ perceived cancer symptoms are reported in Table 2.

Table 1. Comparison of Patients’ Stage of Cancer Before and After Initiating Human Milk Therapy (HMT)

<table>
<thead>
<tr>
<th>Age, y</th>
<th>Gender</th>
<th>Duration of HMT</th>
<th>Other Therapies Used Along With HMT</th>
<th>Cancer Type</th>
<th>Cancer Stage at Initiation of HMT</th>
<th>Cancer Stage at Conclusion of HMT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>61</td>
<td>F</td>
<td>8-12c</td>
<td>Vitamin C, shark’s cartilage, milk thistle, sodium butyrate, turmeric, chemotherapy</td>
<td>Breast</td>
<td>Moderate</td>
</tr>
<tr>
<td>B</td>
<td>80</td>
<td>F</td>
<td>12-16</td>
<td>None</td>
<td>Lung</td>
<td>Advanced</td>
</tr>
<tr>
<td>C</td>
<td>53</td>
<td>M</td>
<td>2c</td>
<td>Vitamin C, herbs, acupuncture, chiropractic, homeopathy, naturopathy, vitamins, minerals</td>
<td>Prostate</td>
<td>Early</td>
</tr>
<tr>
<td>D</td>
<td>60</td>
<td>F</td>
<td>8-12c</td>
<td>Herbs, supplements, music, prayer, acupuncture, essiac tea, bird’s nest soup, chemotherapy, radiation</td>
<td>Lung</td>
<td>Moderate</td>
</tr>
<tr>
<td>E</td>
<td>81</td>
<td>M</td>
<td>7c</td>
<td>None</td>
<td>Lung</td>
<td>Advanced</td>
</tr>
<tr>
<td>F</td>
<td>70</td>
<td>M</td>
<td>3.5c</td>
<td>None</td>
<td>Prostate</td>
<td>Early</td>
</tr>
<tr>
<td>G</td>
<td>86</td>
<td>F</td>
<td>0-3.5</td>
<td>Wheatgrass, herbs from friends</td>
<td>Lung</td>
<td>Advanced</td>
</tr>
<tr>
<td>H</td>
<td>44</td>
<td>M</td>
<td>0-12</td>
<td>Radiation</td>
<td>Lymphoma</td>
<td>Advanced</td>
</tr>
<tr>
<td>I</td>
<td>54</td>
<td>M</td>
<td>8-12</td>
<td>Dietary changes, UCLA trial medication</td>
<td>Colon</td>
<td>Advanced</td>
</tr>
<tr>
<td>J</td>
<td>68</td>
<td>F</td>
<td>8-12</td>
<td>Vitamins, minerals, chemotherapy, radiation</td>
<td>Breast</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

a Self-reported by patient or proxy.
b Received milk from sources other than San Jose Mother’s Milk Bank.
c Consumed raw milk.
d Used proxy.
Table 2. Perceived Cancer Symptoms Before and After Initiating Human Milk Therapy (HMT)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Symptoms Before HMT</th>
<th>Symptoms After HMT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A*</td>
<td>Patient had chemotherapy symptoms: tiredness, nausea, diarrhea. Patient was allergic to cow’s milk.</td>
<td>Patient had no nausea, diarrhea, or tiredness and was not allergic to human milk.</td>
</tr>
<tr>
<td>B*</td>
<td>Patient had difficulty swallowing and eating because of size of tumor.</td>
<td>Patient had no difficulty swallowing human milk. Human milk was easier to digest, improved her QOL, and offered more nutrients. She tolerated liquids better than regular food.</td>
</tr>
<tr>
<td>C*</td>
<td>Patient had elevated PSA levels.</td>
<td>PSA levels dropped 1 month after initiating human milk therapy. No other supplements had changed during this time.</td>
</tr>
<tr>
<td>D*</td>
<td>Patient had trouble swallowing, was very sick and unable to work, and had no appetite.</td>
<td>Patient felt stronger and stayed in remission; cough decreased and respiratory function improved. Patient was able to exercise more to offset fatigue, had increased appetite, and gained weight. Milk donated by family and friends gave patient positive feeling.</td>
</tr>
<tr>
<td>E*</td>
<td>Patient was not a (cow) milk drinker.</td>
<td>Patient was energized by human milk. His energy was not depleted by cancer, and his spirits improved.</td>
</tr>
<tr>
<td>F</td>
<td>Patient practiced watchful waiting.</td>
<td>Patient continued watchful waiting.</td>
</tr>
<tr>
<td>G</td>
<td>Data were unavailable.</td>
<td>Data were unavailable.</td>
</tr>
<tr>
<td>H</td>
<td>Patient had no appetite, couldn’t tolerate food, and was losing weight.</td>
<td>Patient requested and drank milk without coaxing after a couple days. Patient’s stomach felt better; kept milk down. Patient didn’t push milk away like other food.</td>
</tr>
<tr>
<td>I</td>
<td>Patient had weight loss and diarrhea.</td>
<td>Patient had fewer colds and fever and less “gray” appearance. Weight was maintained.</td>
</tr>
<tr>
<td>J</td>
<td>Chemotherapy made patient feel miserable: nauseous, weak, wheezy.</td>
<td>Patient felt stronger and found it easier to get through chemotherapy. She had fewer colds. She feels well and cancer is gone.</td>
</tr>
</tbody>
</table>

Abbreviations: QOL, quality of life; PSA, prostate specific antigen.

* Received milk from sources other than San Jose Mother’s Milk Bank.

** Used proxy.

**Patient Progress**

Two patients were in the early stages of their cancer when they started the human milk treatment, 3 were at moderate stages of cancer, and 5 were in advanced stages of cancer. Three of the patients were in remission, 2 advanced in their stage of cancer, and 5 had died. Of the 5 who died, 3 died within 1 year of initiating the human milk treatment, and 2 died within 2 months (Table 1).

**Source of Information**

All of the patients in this study acquired information about human milk therapy from Internet research. Four had some connection to a person in a human lactation–related field. One patient learned of the treatment through his prostate cancer support group. Two patients were also under the care of alternative therapy clinics that included human milk as part of their CAM treatment plan. The Web research was conducted by spouses and other family members and led them to studies conducted done by Hakansson et al\(^1\) and Svensson et al\(^2\) as well as in vitro studies by Fischer et al\(^2\) and Gustafsson et al\(^3\).

**Dose and Duration**

Prescriptions were obtained from a physician of choice by each patient to initiate human milk treatment. No optimal dose has been determined experimentally, so doses varied from 59 to 355 mL (2-12 oz) per day. Patients received total quantities between 3 and 174 L (100 and 5891 oz) over the course of treatment, which varied from 6 to more than 338 weeks, amounting to a total of 584 L (19 733 oz or 154 gallons) of human milk for the entire study group. Dose and duration varied between participants but were related to stage of cancer at initiation of human milk treatment. The 5 patients who died during treatment were at terminal stages of cancer when they initiated human milk treatment, and they received the smallest overall quantity of milk for less than 3 months. Four patients continue to take human milk for prophylactic purposes. Two of the patients who are in remission and are taking the milk for prophylactic purposes have received the largest overall quantity of human milk for the longest period of time.

The exact dose of human milk consumed by these patients is not known. Four patients reported reducing their dose because of the cost of the milk. At $3 US per ounce processing fee (plus shipping), human milk is relatively expensive, and 2 patients commented that it was the most expensive supplement they took. (This is the price participants paid for milk from the SJMMB. The processing fee range for milk banks that are part of Human Milk Bank Association of North America is...
Only 1 patient was able to bill his insurance, and 1 paid for the milk with disability payments.

All participants received human milk from the SJMMB, but 3 also received milk from other donors. The amount from other donors varied based on availability. One participant commented that it added spiritual value when the milk was a gift. Human milk from additional donors is not included in this study. Two recipients were refused milk from 5 other sources including other milk banks. The reason given was that human milk is not a proven cancer treatment.

Time of day for consuming the milk varied among participants, with 3 not taking it on a regular schedule, 4 taking it on an empty stomach at night, 1 taking it on an empty stomach in the morning, 1 taking it between meals, and 1 taking it after dinner.

Other Therapies

Seven participants took other CAM therapies in addition to the human milk, including vitamin C (n = 2) and acupuncture (n = 2). Other therapies included shark’s cartilage, bird’s nest soup, milk thistle, turmeric, wheatgrass, chiropractic, homeopathy, naturopathy, music, herbs, and vitamins. Two participants were being treated by alternative clinics, which planned a complementary regimen compatible with the chemicals in the conventional medical treatment and based on their laboratory results and symptoms. The clinics recommended a holistic plan including exercise to enhance the chemotherapy, music, prayer, appetite stimulants, hydration tips, and soothing supplements, with a stated goal of achieving peace of mind.

Although 5 of the 10 participants were receiving both conventional biomedicine and CAM treatment, 5 patients opted out of conventional treatment: 2 because of “watchful waiting” during the early stage of their cancer; 2 because radical surgery was the only other option, and 1 because she expected a decrease in QOL from conventional biomedicine. Two surviving patients planned to continue all multiple therapies because something was helping them improve, although they were not sure which treatment it was. One patient asked, “How much does belief help?”

Barriers to Use of Human Milk

Although all cancer patients informed their medical practitioners of their desire to take human milk, some met resistance from a medical professional who felt the therapy was clinically unproven or refused to look at the in vitro research study results. One patient anticipated resistance from her radiologist and chose not to tell him. When the cancer patients met resistance, they reported finding a more supportive practitioner to write their prescription. They wondered aloud how the milk could hurt them or what they had to lose by eating a food safe enough for infant consumption. Some family members were skeptical but were aware of others taking the same treatment and did not interfere with this novel treatment. Four of the 5 terminal patients did not meet resistance. The patients reported that their practitioner supported the human milk therapy because they knew their patient was terminal and felt that this could not hurt them and might help.

Other potential barriers to the use of human milk were the cost, media censure, and taste. The average cost/processing fee of human milk from the SJMMB was $3 per ounce, and shipping costs were applied to shipments more than 30 miles from the SJMMB. Some participants were criticized for taking milk away from babies. One participant discontinued drinking the milk because of the “awful” taste; 2 masked the taste of the pasteurized milk, describing it as an oily undertaste and a slightly cooked taste. Another patient said the human milk had a gamy taste and held her nose and swallowed the milk while reminding herself that it was healing. She also masked the taste with chocolate. Participants who did not like the taste of pasteurized milk signed waivers to receive raw milk. Five who received raw milk from the milk bank or from other sources reported that raw milk tastes delicious, sweet, and lively. One participant described the milk as thick but did not notice the taste. One participant did not like milk otherwise but liked the human milk in a smoothie. Two recipients could drink the human milk but reported being allergic to other milk. One participant’s milk consumption was limited to when a particular caregiver was present.

Expectations

When asked to recall their expectations at the initiation of human milk therapy and to determine whether these expectations had been met, 6 cancer patients reported that they had no expectations. Two hoped that the therapy would strengthen and support their immune system, and they felt that it had. One had hoped for a reversal and that did not happen, and 2 thought it was a long shot and did not expect that it would cure their cancer, which it did not. For 3 patients it offered hope,
either that things would change or that their digestion would improve. One patient was looking for anything that helped. Donor milk was seen as a last-ditch effort when nothing else worked and was worth trying for a “one in a million chance of success.” One patient expected it to taste good and was not prepared for the taste she encountered.

Quality of Life Effects

When considering the more radical, invasive treatments, which might have prolonged her survival, 1 patient opted for the human milk therapy, because it had the potential to improve her QOL even though it was perceived to be an unproven cancer treatment. Another patient noted that although his cancer had not improved, it also had not progressed, and there were no other options. Two other patients noted that although human milk did not cure their cancer, their energy did increase. One patient believed that human milk would speed up and enhance the healing process. Another expected that the human milk therapy would improve his cancer stage, whereas others believed that the milk maintained their health and cited examples of human milk taken for prophylactic use or for stomach ulcers.

Patients’ Assessment of Efficacy of Treatment

Only 1 patient felt that the human milk therapy had no health impact and would not use human milk treatment again unless testing proved its efficacy. The others had no expectation, considered the treatment experimental, and delayed their expectations while watchfully waiting. One participant would take human milk again if the taste was improved, and 1 participant described the human milk therapy recipients as desperate people looking for desperate measures—anything that helps. Another participant did not feel desperate, but he “did not want to die” either. He felt that if there is “a possible million to one chance that it might help,” a patient might want to try it. He proposed the unanswerable question: “Even if the human milk did not cure the cancer, did it stop it from progressing?” Without evidence, “the only benefit (of human milk therapy) is psychological. People are looking for hope. This is a pathway for hope and gives the patient something positive when most things about cancer are negative.”

Discussion

Human milk, according to cancer patients in this study, provided a well-tolerated, energizing therapy that gave them hope for an improved QOL. Physical improvements listed by patients as positive effects of the treatment were numerous: increased energy, immune support, increased strength, improved respiratory function, and improved appetite. Three participants noted that human milk offered nutritional support and additional calories and that it eased the side effects chemotherapy had on their digestive system. The spiritual function of human milk therapy was mentioned when 1 patient asked, “How much does belief help?” Patients in this study agreed with results found by Shapira et al that “some patients may trade survival advantages for better QOL when presented with the choice of alternative outcomes.”

These cancer patients chose to take donor human milk in an attempt to improve their medical care and QOL. Because this is not a randomized, controlled trial, the effects may not be attributable to human milk therapy.

In all cases, Internet research led to the research by Hakansson et al and Svensson et al as well as in vitro studies by Fischer et al and Gustafsson et al; this research is provocative and suggests that treatment with modified human milk proteins has the potential for success as a cancer therapy. Information about CAM therapies is readily available on the Internet, but it is difficult for readers to separate reputable sources from unproven treatments. Human milk is a natural food for all infants and has a long history of safe use with premature and medically challenged infants. These factors may have accounted for its recommendation, despite a dearth of large-scale, in vivo, scientific studies.

Six patients in this study reported using multiple therapies in addition to human milk. Five of the patients did not use conventional cancer treatment while taking the human milk therapy. Verhoef et al found that 5% of cancer patients abandon conventional therapy for alternative methods. Terminally ill patients are reported to be more likely to take unproven, untested substitutes. For 5 of the terminally ill patients in this study, conventional therapies had been exhausted or had unacceptable side effects or significant risks. Patients used CAM because their particular condition could not be treated effectively with conventional medical treatment. Some of the patients in this study reported that the conventional treatment would have decreased their QOL, and their priority was QOL over the possible benefits of conventional treatment with negative side effects.

All participants were honest with their practitioner about taking the human milk therapy, unlike a previous study which reported that CAM use is only disclosed.
to physicians by 46% of cancer patients. The 100% disclosure rate in this study is likely because a prescription is required for receipt of human milk from donor milk banks.

Five of the 10 recipients met resistance from medical professionals when seeking a prescription, especially from oncologists and surgeons. The resistance was selective and determined by the stage of cancer. When patients in earlier stages of cancer met resistance, they were told that human milk therapy is an unproven treatment. Terminally ill patients’ choice to take human milk was supported by medical professionals who stated that the therapy might help and could not hurt.

Participants in this study reported being criticized by physicians and a newscaster for taking human milk destined for premature infants. This appears to be an unsubstantiated opinion. The milk given to adults is mature milk (milk from mothers of older babies) and does not affect the supply for premature babies. Priority for distribution of donor human milk is determined by the Human Milk Bank Association of North America (HMBANA) guidelines. According to these guidelines, premature babies or term infants have priority over adult cancer patients in receipt of donor milk.

The total quantity of 584 L delivered to the 10 recipients in this study from September 1999 to December 2005 amounts to less than 2% of the total 28 389 L (958 936 oz) delivered to all recipients from SJMMB during this same period (data from the SJMMB annual report 2005). More important, the SJMMB average amounts represent total amounts requested and delivered and do not reflect the amount of milk available. The average amount of milk received by adult cancer patients from all 11 HMBANA member milk banks in 2005 would be less than 4.0% to 4.5% of donor milk distributed in that year (listed as an adult illness in data from the HMBANA annual report 2005). More important, the SJMMB average amounts represent total amounts requested and delivered and do not reflect the amount of milk available. The average amount of milk received by adult cancer patients from all 11 HMBANA member milk banks in 2005 would be less than 4.0% to 4.5% of donor milk distributed in that year (listed as an adult illness in data from the HMBANA annual report 2005). Adult illness includes cancer and immune deficiencies.

Six cancer patients in the present study said that the cost/processing fee for the milk including shipping was a reason for reducing the dose or seeking alternate sources of human milk. Eisenberg et al. found that 58% of CAM users paid for alternative therapy entirely out of pocket. Even though 9 recipients could not bill their insurance for the processing fee for the donor milk, they continued to use this therapy. Previous studies also suggested that cost is not a deterrent to CAM use. The findings in this study suggest that some cancer patients were determined to use human milk therapy despite the high cost, lack of insurance coverage, or discouragement by the conventional medical community. Barrett reported a national trend toward coverage of CAM therapies by insurers, mainly because of consumer demand. The insurers’ main concern is lack of research on efficacy and lack of standards of practice. Randomized trials of human milk therapy are needed to evaluate the effectiveness of this potential therapy for various types of cancer. If human milk therapy is shown to be effective, insurance companies should include this therapy in their cancer treatment and QOL programs.

Study Limitations

There are some limitations to this study. The study is retrospective and subjective and depends on the patient’s or proxy’s memory and on the mode of questioning. Although the sample size is limited, the qualitative data provided by participants provide useful insights. QOL measurement and open-ended questioning generate large amounts of data. Combining this data in a concise way may have affected the interpretation of the results, and the process of tabulating subjective responses may introduce human errors.

Although the amount of milk delivered to the patients is known, the amount of milk consumed and the amount shared or received from other sources are not certain. As a result, no quantitative measurement of milk consumption is included in the study results. The amounts presented in this study may or may not be accurate, so it is difficult to draw conclusions based on them. Some patients took other treatments concurrently with the human milk, and all conventional cancer treatments varied. Because multiple therapies were taken, no results can be specifically attributed to human milk therapy.

Family proxies were needed for half of the responses in this study. According to the findings of Tang and McCorkle, cancer patients and their caregivers agree moderately well (r > 0.60) on the patient’s QOL, and proxies can be considered reliable alternates as sources of data for terminal cancer patients on objective questions, whereas they showed moderate to poor agreement on subjective questions. Two of the 5 patients lived with the family proxy, and the other 3 proxies were in frequent contact with the patient. Given this close contact, their answers were likely to be in strong agreement for observable questions. The QOL answers in this study are subjective, and it is possible that they do not perfectly represent the patients’ responses, because data obtained from a proxy may or
may not reflect the feelings the patient would have expressed. These study results may not be generalizable to other populations of cancer patients using human milk therapy.

**Conclusions**

The subjects in this study were willing to experiment with this unproven treatment despite the relatively high processing fee for the human milk, lack of insurance coverage for the fee, an unpleasant taste to some, and discouragement from the conventional medical establishment for others. Although the patients did not initially request the human milk for its life-enhancing effects, they found that it eased the side effects of cancer treatment and the ill effects of their condition. Dosage was reduced by some participants because of the high processing fee for the milk, possibly diluting the effect a higher dose or longer duration might have had on their results.

Human milk was found by cancer patients in this study to be well tolerated and nutrient dense. Some found that it eased their difficulties swallowing and was soothing to the gastrointestinal tract. This finding is very interesting and worth pursuing in future studies.

Participants reported that human milk reduced the nausea, weakness, and general lethargy that they experienced after initiating chemotherapy. Patients reported an improved level of function and physical improvements, such as increased energy, immune support, increased strength, improved respiratory function, and increased appetite, as a result of taking human milk therapy. Their recovery was full of uncertainty, and they sometimes felt like things were out of their control. This treatment option offered them hope and a sense of control and responsibility in their treatment plan. Satisfaction with one’s QOL may be more important than cancer outcomes and may improve a patient’s medical care overall. Participants in this study who were in moderate to advanced stages of multiple cancers reported improvements in their QOL measures in the physical, psychological, and spiritual domains compared with what they experienced before taking the human milk treatment. Patients in early stages of cancer or in remission continued to take the human milk for prophylactic purposes because they felt it had improved their general well-being. In these cases, the human milk therapy was associated with a perception of improved QOL for the cancer patients.

Larger samples are needed from randomized trials that test the effectiveness of human milk in the treatment of human cancers. If human milk therapy is shown to be effective, insurance companies should include this therapy in their cancer treatment and QOL programs. Under HMBANA guidelines, premature and term infants are given priority over adult cancer patients for receipt of donor human milk. Currently, interested milk banks are able to meet the needs of cancer patients requesting donor human milk from available sources. It is unknown at this time whether other sources could be tapped to meet increased demands for human milk.

Three recipients in this study supplemented their human milk supply with milk from nursing mothers in their community (HMBANA does not recommend use of milk from unscreened donors). It is possible that human milk is more widely used than is known through milk bank data. Surveys of area clinics and social organizations are needed to determine a more representative number of total requests for human milk by cancer patients. More data would reveal a trend of the total number of requests for human milk and would clarify whether total requests for human milk are increasing, decreasing, or staying the same. This larger pool of data would offer a clearer picture of cancer patients’ value for human milk therapy and would confirm whether there is a need for large-scale, in vivo scientific studies on the effects of human milk therapy on cancer patients’ QOL.

**References**

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