ABSTRACT

Objectives: This research study assessed perceived changes in quality-of-life measures related to participation in complementary services consisting of a variety of nontraditional therapies and/or programs at Pathways: A Health Crisis Resource Center in Minneapolis, Minnesota. Design: Survey data were used to assess perceived changes participants ascribed to their experience with complementary services at Pathways. Quantitative data analysis was conducted using participant demographics together with participant ratings of items from the “Self-Assessment of Change” (SAC) measure developed at the University of Arizona, Tucson. Qualitative data analysis was conducted on written responses to an additional survey question: “To what extent has your participation at Pathways influenced your healing process?” Results: Quantitative findings: Participants reported experiencing significant changes across all components of the SAC measure. Qualitative findings: Responses to the open-ended survey question identified perspectives on the culture of Pathways and a shift in participants’ perceptions of well-being based on their experience of Pathways services. Conclusions: Participation in services provided by the Pathways organization improved perceptions of quality of life and well-being and led to more active involvement in the experience of a healing process.

SINOPSIS

Objetivos: Este estudio de investigación ha evaluado los cambios percibidos en las mediciones de calidad de vida relacionadas con la participación en servicios complementarios que consisten en una variedad de tratamientos no tradicionales o programas en Pathways: un centro de recursos para crisis sanitarias en Minneapolis (Minnesota).

Design: Se utilizaron datos de encuestas para evaluar los cambios percibidos que los participantes atribuyeron a su experiencia con los servicios complementarios en Pathways. El análisis de datos cuantitativos se llevó a cabo utilizando los datos demográficos de los participantes junto con las puntuaciones...
INTRODUCTION

*Human beings by changing the inner attitudes of their minds can change the outer aspects of their lives.*

—William James

Life experiences often change dramatically for those diagnosed with a life-threatening or chronic illness (ie, serious health challenges). Many are no longer able to work and find that their lives now revolve around medical appointments and therapies, leaving little time or energy for living a normal life. Exhausted and bewildered, individuals sometimes stumble upon or actively seek approaches to living beyond traditionally accepted or expected limitations of their illnesses. There is mounting evidence to suggest that nontraditional approaches to dealing with a medical crisis such as emotional support, meditation, use of imagery, a focus on spirituality, and other attitudinal factors can contribute to an individual’s healing process.1-3

Complementary care services typically focus on dealing with stress, identifying fears, reframing hope, and regaining control. Such programs often move individuals toward a deeper understanding of life and enable those afflicted to find meaning in their lives when they most need it. Even when physical recovery and cure are unlikely, healing may occur on psychological, emotional, and spiritual levels.1,4,7 Severe health challenges can inspire individuals to learn new life skills such as compassion, spirituality, courage, resilience, functionality, and wisdom, thereby enhancing their quality of life.8 The Institute of Noetic Sciences (IONS, Petaluma, California) has spent more than a decade focusing on the science of everyday life transformation and has found that following the use of complementary services, there is often a shift in perspective and a feeling of profound change in one’s way of being.6,7

Serious illness impacts not only the social and economic lives of millions of Americans (burden of dis-...
patient’s voice central” and being guided by the interests and outcomes of patients and caregivers faced with multiple health challenges.\textsuperscript{17,18}

Pathways is a non-profit, volunteer-sustained organization that provides, free of charge, a variety of one-to-one nontraditional therapy sessions (eg, healing touch, Reiki, reflexology, acupressure, massage) as well as health coaching, support groups, educational classes, and practice groups such as yoga and meditation for those facing serious health challenges (www.pathwaysminneapolismn.org). Pathways is not connected to a medical clinic or hospital nor is it part of a particular healthcare system. Its services are considered complementary to conventional treatment. Pathways was created by a group of people who believed that those with serious health problems needed a place to explore a variety of healing modalities and experience the benefits of active participation in a healing process. Presently, more than 150 individuals volunteer at Pathways, 120 as providers of complementary services and 30 as support staff.

Pathways participants are dealing with multiple health issues surrounding a diagnosis such as cancer, cardiovascular disease, or multiple sclerosis—diseases that often include depression, chronic pain, anxiety, and fatigue. Annually, more than 6800 individuals participate in Pathways’ services. Those who provide services at Pathways are credentialed and experienced in their particular service; each is carefully evaluated by a committee of the board of directors.

Many individuals learn about Pathways from those who value the services they have experienced; others are referred by their healthcare providers. After participating in an orientation session about the mission and purpose of Pathways, individuals self-select the services they wish to explore.

The research project reported here was designed to provide evidence for the value of complementary services to individuals with a variety of health challenges. The specific data collected assessed perceptions of healing and changes in well-being reported by participants following the use of Pathways services.

\textbf{METHODS}

This research project was approved by the University of Minnesota Institutional Review Board. Both quantitative and qualitative analyses were used to identify perceptions of participants who used Pathways services between 2007 and 2009. A survey was initially pilot-tested with 15 individuals and thereafter mailed to 419 participants. An accompanying letter asking for participation with informed consent described the purpose of the survey, the basis for selecting the individuals who received it, and an estimate of how much time the survey would take to complete. Confidentiality and anonymity were assured, and participants were informed that all information would be aggregated before being shared.

One hundred eight (108) completed surveys were returned from the initial mailing. A second mailing was sent to an additional 114 participants, resulting in an additional 18 responses, for a total of 126 surveys. Twenty-two individuals chose to not complete the SAC portion of the survey.

\textbf{Quantitative Analysis}

The quantitative component of the project consisted of demographic data supplied by each participant plus each participant’s responses on items from the SAC measure (hereafter, the SAC instrument). In the context of the present study, the SAC instrument was used to retrospectively assess the impact of Pathways’ complementary care services. The SAC was developed under a National Center for Complementary and Alternative Medicine (NCCAM)–funded research project with Cheryl Ritenbaugh, PhD, MP, University of Arizona, Tucson, as the principal investigator and other team members from universities in Florida, Oregon, Michigan, and Canada. This team used extensive interviews and focus groups in the development of the SAC with input from people facing serious health challenges who had participated in a variety of CAM services.\textsuperscript{17} Ritenbaugh et al developed the SAC instrument with the goal of assessing the patient’s perception of effects beyond direct medical treatment goals. These emergent outcomes included unanticipated shifts in perceptions of well-being, energy, clarity of thought, emotional and social functioning, lifestyle patterns, inner life, and spirituality, all outcomes that may or may not have been part of the expectations of those experiencing Pathways’ services. A guiding premise of the work of the Ritenbaugh et al group was “that the patient’s perception of personal changes associated with a CAM intervention is one of the most relevant measures of impact.”\textsuperscript{17(p8)}

Early in the survey development process, Ritenbaugh et al noticed that people reported “surprise” at changes in their lived experience and shifts in their “internal frame of reference” as a result of their participation in complementary services. This observation motivated the use of a “retrospective pre-test design.”\textsuperscript{17} This approach has been previously used for the evaluation of learning outcomes in educational and training settings and has been shown to (1) control for response shift bias (reconceptualizing the construct under investigation between the pretest and the posttest) and (2) minimize both overestimation and underestimation of change.\textsuperscript{19} As reported by Ritenbaugh et al, the evaluative measure termed \textit{retrospective pre-test} has typically been used when the experience of change is perceived to be most salient.\textsuperscript{19}

The SAC development project was presented as a 90-minute symposium at the North American Research Conference on Complementary and Integrative Medicine (NARCCIM) in Minneapolis, Minnesota, in May 2009. As a result of this presentation, a larger collaborative group was formed for implementation and further evaluation of the instrument in diverse health-
care settings. Minneapolis Pathways is one of these collaborating projects.

The SAC version used in this research included 18 word pairs that anchor relative positive and negative extremes of key domains of change. Each word pair is presented in a visual scale format on a 100-mm analog scale (Figure 1). According to Ritenbaugh et al, these word pairs encompass five characteristics (domains) of well-being: physical (ph); emotional (em); cognitive (co); social (so); and spiritual (sp), as categorized by the Ritenbaugh team. During the process of categorization, a sixth domain was discovered, which the team termed ‘whole person (wp)’ because the items seemed to bridge several domains.”19 Participants in the Pathways research were instructed to mark each line to indicate where they were before (B) they came to Pathways and where they are now (N). For analysis, the 100-mm line connecting each word pair is measured from the left edge to B (before coming to Pathways) and N (now) for data entry purposes. The measures of interest for this research are based on the distance between B and N for each word pair, which reflects participants’ shifts in their perceptions of well-being as reflected by that word pair. The completed SAC portion of each participant’s survey was mailed to Ritenbaugh and her team who calculated the data measurements and sent them to our statistician. Using Excel (Microsoft Corp, Redmond, Washington) and Stata (Stata Corp LP, College Station, Texas) software packages, descriptive statistics were developed and paired t-tests were computed for each word pair based on mean scores of participants’ ratings.9

Use of the SAC instrument contributes data on the perceived effectiveness of complementary services and in this context, provides Pathways with information about the benefits participants report as a result of their experience at Pathways. (See Figure 1 for an illustration of the SAC instrument).

Qualitative Analysis

In order to gain a more complete understanding of the influence of Pathways experiences on participants in their own words, an open-ended question was added to the survey. A qualitative analysis was then undertaken of participant’s written responses to the survey question, “To what extent has your participation at Pathways influenced your healing process?” A group consisting of the four authors and the Pathways director conducted this analysis.

The analysis process began with each team member independently sorting responses of each participant into as many categories as seemed appropriate. This process resulted in 23 categories. The team then met to identify themes (major categories) of participant responses.20,21 A master list of themes was constructed based on discussion of each team member’s coded data. This process resulted in three major themes (Pathways’ healing culture, exploring Pathways’ services, and a perceived shift in participants’ experience of their condition).22 Fourteen subthemes were identified with one or more subthemes falling under each of the three major themes.

RESULTS

Quantitative Findings

Table 1 presents the demographics of survey respondents. Data from Table 1 indicate that participants in the present study were predominantly women,

Table 1 Demographics of Survey Participants (N=108)

| Age, y   | Marital Status |
|----------|----------------|
| Under 20 | 0% Single      |
| 20-40    | 11% Married    |
| 41-60    | 60% Divorced   |
| 61-75    | 23% Widowed    |
| Over 75  | 6% Partnered   |
|          | Separated      |

| Sex       | Education       |
|-----------|-----------------|
| Female    | 85% High school/GED |
| Male      | 15% Some college/tech |
|           | College graduate |
|           | Advanced degree |

| Total Household Income, USD | Employment |
|-----------------------------|------------|
| Less than $12000            | 20% Full-time |
| $12000 to $24999            | 28% Self-employed |
| $25000 to $39999            | 16% Part-time |
| $40000 to $74999            | 27% Unemployed |
| More than $75000            | 9% Health leave |
|                             | On disability |

| Serious Illnesses |
|-------------------|
| 1. Arthritis (all types) | 17.5% |
| 2. Asthma/respiratory disease | 10.0% |
| 3. Cancer | 40.0% |
| 4. Chronic pain | 26.2% |
| 5. Depression/anxiety disorder | 32.5% |
| 6. Diabetes | 4.8% |
| 7. Heart/CV disease | 7.9% |
| 8. HIV/AIDS | 1.6% |
| 9. Other serious health issues | 58.7% |

Abbreviations: CV, cardiovascular; GED, General Educational Development degree; tech, technical school.
mainly over 40 years of age, with diverse incomes, employment, and disability. Ninety-four percent had some college or higher educational experience. In response to the question, “What health-related issue brought you to Pathways? (please circle all that apply),” the data indicated that most participants were dealing with multiple health issues. Participants reported using a wide variety of Pathways’ services throughout the 2 years represented by the data collected. When asked “During a given month, how often did you use the resources at Pathways?” the majority (54%) indicated two to four times; 19%, five to 10 times; 11%, more than 10 times; and 15% only once a month.

Of the 126 individuals who returned the survey, 104 completed the SAC component. Twenty-two individuals noted a reason for not completing the SAC measure, the most common being that they felt they had attended too few sessions for this to be meaningful or that they had not attended in the previous year and therefore believed that “now” was not a relevant time point for assessment.

As shown in Table 2, analysis of the SAC measure indicated that the mean ratings of Pathways participants changed from “before” to “now” on every word pair and for every domain of well-being (indicated in parentheses after each word pair). Table 2 also provides the mean ratings for B and N, the difference, C (change between B and N), and the standard deviation of the change in rating organized by magnitude of change for each word pair. The numbers in the table indicate the mean rating on a 0 mm to 100 mm visual analogue scale for each word pair.

The results in Table 2 show positive changes for each of the 18 word pairs in each of the six domains identified by Ritenbaugh et al. The change in the mean self-assessment ratings, from before use of the services to date of the survey ranged on the visual analogue scale from 38.3–29.7 (top half) to 28.1–17.0 (lower half) with a median of 26.77. (analog scale, 100 mm length). In what follows, we describe in more detail participants’ responses to the items in each of the Ritenbaugh et al domains shown in Table 2.

#### Whole-person Domain (items 1, 2, 3, 5, 9, and 14 in Table 2).

The Ritenbaugh team has argued that whole person changes are deeply personal, likely only evident to the participant, less visible to others, and hence, less

### Table 2

| Word Pair | Before | Now | Change | SD |
|-----------|--------|-----|--------|----|
| Not sleeping well (ph) | | | | |
| Exhausted (ph) | | | | |
| Dull senses (ph) | | | | |
| Scattered (cog) | | | | |
| Stuck (wp) | | | | |
| Overwhelmed (wp) | | | | |
| Hopeless (sp) | | | | |
| Blaming (wp) | | | | |
| Closed-hearted (em) | | | | |
| No energy (ph) | | | | |
| Isolated (so) | | | | |
| Depressed (em) | | | | |
| Anxious (wp) | | | | |
| My body does not recover quickly (ph) | | | | |
| Defined by my illness/problems (wp) | | | | |
| Broken (wp) | | | | |
| Not on a spiritual path (sp) | | | | |
| Unbalanced (wp) | | | | |

Abbreviations: co, cognitive; em, emotional; ph, physical; so, social; sp, spiritual; wp, whole person.
TABLE 2 Mean Self-assessment Ratings for Each Word Pair Before and Now

| Word Pair                              | Mean Before | Mean Now | Change (Now-Before) | Standard Deviation of Change | Significance |
|----------------------------------------|-------------|----------|---------------------|-----------------------------|--------------|
| 1. Overwhelmed–Empowered (wp)          | 25.8        | 64.1     | 38.3                | 28.1                        | P < .001     |
| 2. Stuck–Letting Go (wp)               | 29.5        | 66.7     | 37.3                | 29.3                        | P < .001     |
| 3. Anxious–Calm (wp)                   | 32.9        | 66.2     | 33.3                | 27.0                        | P < .001     |
| 4. Exhausted–Energized (ph)            | 26.3        | 57.3     | 31.0                | 27.8                        | P < .001     |
| 5. Unbalanced–Balanced (wp)            | 37.9        | 68.3     | 30.4                | 28.9                        | P < .001     |
| 6. Depressed–Joyful (em)               | 37.1        | 66.9     | 29.8                | 27.3                        | P < .001     |
| 7. Hopeless–Hopeful (sp)               | 39.1        | 68.9     | 29.8                | 28.4                        | P < .001     |
| 8. Scattered–Focused (cog)             | 30.7        | 60.5     | 29.8                | 29.4                        | P < .001     |
| 9. Broken–Whole (wp)                   | 40.6        | 70.3     | 29.7                | 30.9                        | P < .001     |
| 10. No Energy–Full of Energy (ph)      | 32.2        | 60.3     | 28.1                | 29.4                        | P < .001     |
| 11. Defined by Illness/Problems (wp)–Not Defined by Illness/Problems (co) | 42.7 | 70.3 | 27.6 | 30.0 | P < .001 |
| 12. Isolated–Connected (so)            | 40.5        | 67.7     | 27.2                | 27.8                        | P < .001     |
| 13. Dull Senses–Vibrant Senses (ph)    | 37.4        | 64.5     | 27.1                | 30.0                        | P < .001     |
| 14. Blaming–Forgiving (wp)             | 49.9        | 75.3     | 25.4                | 30.4                        | P < .001     |
| 15. Closed-hearted–Open-hearted (em)   | 52.1        | 76.3     | 24.1                | 29.1                        | P < .001     |
| 16. Not On A Spiritual Path–On a Spiritual Path (sp) | 55.3 | 77.2 | 21.9 | 30.0 | P < .001 |
| 17. Not Sleeping Well–Sleeping Well (ph) | 37.3 | 59.1 | 21.8 | 27.8 | P < .001 |
| 18. Body Does Not Recover Quickly–Body Recovers Quickly (ph) | 39.0 | 56.0 | 17.0 | 28.6 | P < .001 |

Abbreviations: co, cognitive; em, emotional; ph, physical; so, social; sp, spiritual; wp, whole person.

measurable using more traditional survey instruments.17

Five of the seven word pairs in this domain demonstrated relatively high average change ratings of 38.3 to 29.7 with “overwhelmed-empowered” and “stuck-letting go” identified as the most distinct indicators of their self-assessed change. The remaining two items (9 and 14) revealed less perceived change (27.6, 25.4). The before rating for “blaming/forgiving” (14) was higher than any of the other whole person word pairs, indicating that “blaming” by itself does not accurately describe this group’s self-assessment. Interestingly, responses indicate a significant change toward “forgiving.”

Physical Domain (items 4, 10, 13, 17, and 18 in Table 2). Changes in the physical domain are often more tangible to participants, their support persons, and providers.17 Somewhat surprisingly, only one of the items (word pairs) in the physical domain fell into the top half of the change scores shown in Table 2 (“exhausted-energized”), while the remaining items indicated less relative change. Perceptions about “the body recovers quickly” was relatively high on “spiritual path” before their Pathways experience, they also reported a significant change in their spiritual experience.

Emotional Domain (items 6 and 15 in Table 2). Changes in the emotional/affective domain reflect a participant’s experiential journey from the emotional turmoil that often accompanies serious illness to a new, renewed, or different level of being that develops over time.17 Two word pairs fell into this domain, one ranked in the top half of Table 2 and the other in the lower half of all word pairs. Participants rated themselves as being more joyful (and less depressed) after Pathways services. While the ratings for “closed-hearted” were relatively high before, participants nevertheless rated themselves as more “open-hearted” after experiencing Pathways’ services.

Social and Spiritual Domains (items 7, 12, and 16 in Table 2). According to Ritenbugh et al, word pairs falling into the social and spiritual domain represent relatedness to self, to others, and to a higher power.17 Three word pairs fell into these domains; only one (“hopeless-hopeful”) was in the top half of change scores. Though participants rated themselves relatively high on “spiritual path” before their Pathways experience, they also reported a significant change in their spiritual experience.

Cognitive Domain (items 8 and 11 on Table 2). Cognitive abilities reflect skills that are needed to sustain attention, solve problems, and carry out tasks.17 When one is seriously ill, these skills are often compromised, hence improvement is an important aspiration. One cognitive word pair (“scattered-focused”) fell in the top half of change scores. Ritenbaugh’s team determined that “defined by illness/problem” (11) belonged in the whole person domain and that “not defined by illness/problem” was in the cognitive domain. On average, participants saw themselves as being more “scattered” than “defined by their illness” before their
Pathways experience with similar shifts to a more positive perspective.

Qualitative Findings
All survey participants (N=126) provided written responses to the survey question, “To what extent has your participation at Pathways influenced your healing process?” As described previously, responses to this question fell into three major themes: (1) what participants experienced when they entered the Pathways healing culture, (2) what participants experienced as they explored Pathways services, and (3) ways participants reported being different after immersion in Pathways culture and services. Figure 2 presents examples of participant statements illustrating the subthemes within each of the three major themes.

Pathways Healing Culture. Participants reported that their Pathways experience began with its purposefully created healing space and extended to include the connections participants made with others with similar challenging experiences. Participants also commented about the support that Pathways provided for caregivers, the safety that participants and caregivers experienced, and the wealth of available resources.

Exploring Pathways Services. Having discovered Pathways, participants design a personalized experience that could include establishing new roles and connections, exploring new ways of healing, and using resources that encourage the reclaiming of personal power. Many participants reported taking on new roles, such as becoming volunteers and finding new friendships. Pathways providers and services enabled participants to accept their life circumstances and assisted them in moving forward with their lives. Many participants reported that Pathways services led to significant personal change.

Shifting Being. Once participants have experienced the healing culture of Pathways, they often reported finding themselves with a new perspective; they become someone they have not known themselves to be. Participants reported feeling safe and open to trust, gratitude, and love. In this state of well-being, participants felt they were better able to cope, accept, and forgive. Finding hope and renewed energy is critical to those facing serious health issues. Participants indicated that they now felt empowered to face challenges.
they might have previously avoided and reported developing a preventive mentality for dealing with core issues and future health challenges.

**DISCUSSION**

The SAC instrument used in the present study was designed to assess individual perceptions of personal changes associated with complementary services (rather than relying upon a provider's viewpoint of therapy effectiveness), thereby providing needed data on the gap between published studies showing little efficacy with standard outcome measures and patients' reports of substantial benefits. In the present study, quantitative analysis of data from the SAC instrument affirmed that participating in the services provided by Pathways was associated with improved self-assessment on a variety of quality of life measures, with the greatest change being reported in the SAC whole-person domain.

According to Ritenbaugh et al, changes in ratings on word pairs in the whole-person domain did not happen in isolation and are associated with improvement in all word pairs within this domain. This association was found to be true of the top five word pairs that showed a change rating of more than 30. (“overwhelmed/empowered,” “stuck/letting go,” “anxious/calm,” “unbalanced/empowered”). The physical domain word pair “exhausted/energized” was also in the top 5 change scores. The perception of being “overwhelmed,” “stuck,” and “exhausted” was assessed to be the most salient of the difficulties participants faced before coming to Pathways. These perceptions changed significantly with participation.

The qualitative data of our study indicated that participants felt free to experiment and discover new areas of interest while exploring a variety of Pathways' services. As their time at Pathways continued, participants reported subtle and quiet shifts in their way of being as well as a heightened experience of qualities such as trust, support, and gratitude. Many participants reported taking on new roles such as volunteering or teaching classes and discovering and using self-empowering resources. Participants also reported feeling that they were on a different journey from what they had anticipated when they first arrived at Pathways. On this journey, they learned new coping skills, including the value of forgiveness and having renewed hope and energy. Some reported they began to develop a preventive mentality by healing core issues in their lives.

**LIMITATIONS**

The results reported here are limited by the nature of the self-report instrument employed, the relatively low survey response rate, and the size and demographics of the Pathways population. Because participants choose to experience different Pathways' services rather than follow a specific therapeutic protocol, no claims can be made that a particular round of therapies produced specific life changes. Personal perceptions are the only confirmation of the therapeutic efficacy of the changes in the quality of life that participants in the present study experienced. While the SAC instrument is an innovative means to assess how such perceptions changed as a result of using Pathways services, 22 participants did not complete the SAC portion of the survey, primarily because the before/now retrospective format did not seem appropriate to their experience.

These limitations suggest that assessments of the results of complementary services such as those provided by the SAC instrument may need to be extended to clearly specified programs over identifiable periods of time. Studies in which participant perceptions are assessed before as well as after the experience of CAM services (rather than in a retrospective format such as was done here) would be an important contribution of future research.

**CONCLUSIONS**

Though a number of studies have been published on the use, cost savings, and effectiveness of a more integrated approach to healthcare, this study is, to our knowledge, the first to use a survey instrument (the SAC) to capture shifts in perceived well-being that extend beyond the resolution of specific health symptoms. Information about shifts in perceptions can be an important guide to the development of programs and services, adding insights to the more qualitative meanings that participants report as a result of their experience of complementary services. It is such shifts that often foster adherence to beneficial lifestyle changes, which, in turn, can lead to an improved quality of life and enhanced health outcomes.

Despite the limitations of the present study, we have demonstrated an important beginning for what can be learned from an assessment of the perceptions of individuals who use complementary services in the context of health crisis needs. Changes in quality of life measures may be associated with other measures of interest to the healthcare system such as patient satisfaction, compliance with treatment regimens, and participation in healthy lifestyle changes needed for disease management, decreased medication use, and fewer hospitalizations. The SAC instrument offers a means of evaluating changes in overall well-being that may result from complementary services that are not often part of medical treatment. The instrument offers a new way of assessing how individuals perceive change and a measureable indicator of how far they have come in their healing process. Person-centered outcome evaluation can be enriched through the use of the SAC instrument. More such work needs to be done.

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