

## Integrative Health Care: How Can We Determine Whether Patients Benefit?

MARJA J. VERHOEF, Ph.D.,<sup>1,2</sup> ANDREA MULKINS, M.Sc.,<sup>2</sup> and HEATHER BOON, Ph.D.<sup>3</sup>

### ABSTRACT

**Objective:** Evaluation of integrative health care (IHC) models is becoming increasingly important. One of the areas that requires further attention is the development of an appropriate set of outcome measures. The purpose of this study was: (1) to identify how cancer patients phrase and frame the beneficial outcomes they experienced from IHC, and (2) to develop recommendations for an appropriate outcome measures package for evaluation of IHC.

**Design:** This study involved two different parts: (1) a secondary analysis of qualitative data consisting of transcripts from 42 personal interviews and three focus groups from previous studies related to IHC use by cancer patients; and (2) a content analysis of goal-setting data collected from patients attending an IHC clinic to categorize the type and range of their treatment goals.

**Results:** Six types of benefits were identified: physical well-being, change in physiological indicators, improved emotional well-being, personal transformation, feeling connected, global state of well-being, and cure. Types of goals identified by patients confirmed these benefits and include: to improve state of being, to be cancer free, to have more energy, more effective pain management, and improved quality of life.

**Conclusions:** A patient's perspective is crucial in understanding the process and outcomes of intentional self-healing. Assessing self-identified goals suggests the need for patient empowerment through participation in outcome evaluation. We present recommendations for an appropriate outcomes package that is relevant, practical, and based on patient experiences.

### INTRODUCTION

The lack of appropriate outcome measures to assess the benefits of integrative health care (IHC) has been identified repeatedly and continues to plague IHC research.<sup>1</sup> It has been argued that investigating the outcomes of IHC requires a conceptual framework of outcomes that reflect patients' lived experiences and acknowledges both the process and outcome components of the intervention. Because IHC modalities address the full scope of a patient's life, outcome measures should not be limited to "health-related" quality of life or absence of disease, but should also address levels

of wellness.<sup>2</sup> Currently, there are few scales that adequately assess "wellness" as a viable and intended outcome of IHC. While increasing attention is being paid to this topic, more work is needed to develop a comprehensive package of outcome measures.

The Tzu Chi Institute for Complementary and Alternative Medicine (TCI) was an integrative health care clinic which operated in Vancouver, British Columbia (1998–2003). Its mission was to assist people in making positive health changes. The TCI followed a three-pillar approach to wellness by providing comprehensive clinical services, operating an information resource center and conducting re-

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<sup>1</sup>Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada.

<sup>2</sup>Tzu Chi Research Group, Vancouver, British Columbia, Canada.

<sup>3</sup>Faculty of Pharmacy, University of Toronto, Toronto, Ontario, Canada.

search to assess the outcomes of its program. Patients tended to have complex health histories, present with multiple risk factors, and report three or more chronic health conditions.<sup>3</sup> The TCI closed its doors in the spring of 2003 on what was a unique “living laboratory” for studying the process and outcomes associated with a new model of health care delivery.

Evaluation of the Integrative Care Program at the TCI was a vital component of its mandate. However, many of the outcomes of the Integrative Care Program that were evaluated were similar to those of any mainstream health care delivery program. They included alleviating symptoms of disease, improving quality of life, and patient satisfaction (Table 1). This selection of conventional measures was attributed to several factors. Most importantly, the TCI was, for a major part, dependent on funding from a number of conventional organizations, which influenced its approach to measuring outcomes.

Over the years, it became clear to the research team that only a few of the initial measures were effective in capturing the core elements of the Integrative Care Program. Patient feedback indicated that several patients perceived the outcome measure surveys to be irrelevant to their TCI experience and a significant burden to complete (e.g., the social support survey). Some individuals felt the questionnaire reinforced feelings of loneliness and isolation. The required completion of 6–7 surveys on three separate occasions negatively impacted the response rate. In addition, some scales (e.g., the patient satisfaction survey) did not allow summary scores, which made it difficult to analyze the data. For these reasons, the research focus underwent changes with a goal of deepening our understanding of the process of IHC for

the TCI’s patients. A revised package (Table 2) was implemented prior to closure. Unfortunately, operations at the TCI ceased before there was an opportunity to collect sufficient data to evaluate the revised outcomes package.

In keeping with the TCI’s mission to develop appropriate, patient-relevant outcome measures for the evaluation of IHC, we felt that a first step would be to determine what individuals using IHC identified as being important outcomes to measure. The objectives of this study are: (1) to identify how cancer patients phrase and frame the beneficial outcomes they experienced from IHC, and (2) to develop recommendations and suggest appropriate outcome measures for the evaluation of IHC optimal healing models.

## METHODS

The study consisted of two separate parts using different data sets. First, a secondary analysis of qualitative data was conducted using transcripts of three focus groups (including 10 individuals in total) and 42 personal interviews from several previous studies related to IHC or complementary and alternative medicine (CAM) use and cancer (Table 3). About 70% of these interactions took place in integrative care facilities in Vancouver, British Columbia. The majority of participants had attended an IHC clinic. However, individuals who used CAM but not IHC each spoke about putting together their own CAM package by using a number of CAM and conventional therapies at one time.

An interpretative, qualitative methodological approach<sup>4</sup> was used throughout the data analysis. This approach provided a means of exploring the lived experience of partici-

TABLE 1. MEASURES INCLUDED IN THE TCI’S INTEGRATIVE CARE PROGRAM’S OUTCOMES PACKAGE

<i>Outcome measure</i>	<i>Time points</i>
(1) Quality of life (SF-36) <sup>a</sup>	Baseline, 6 and 12 months
(2) the General Perceived Self-Efficacy Scale <sup>b</sup>	Baseline, 6 and 12 months
(3) the Multidimensional Health Locus of Control Scale <sup>c</sup>	Baseline, 6 and 12 months
(4) Sense of coherence <sup>d</sup>	Baseline, 6 and 12 months
(5) MOS social support survey <sup>e</sup>	Baseline, 6 and 12 months
(6) Picker Patient Satisfaction survey <sup>f</sup>	6 and 12 months
(7) Numeric Pain Distress Scale	Baseline, 6 and 12 months

<sup>a</sup>Schwarzer R, Jerusalem M. Generalized self-efficacy scale. In: Weinman J, Wright S, Johnston M, eds. *Measures in Health Psychology: A User’s Portfolio. Causal and Control Beliefs*. Windsor, UK: NFER-NELSON, 1995:35–37.

<sup>b</sup>Wallston BS, Wallston KA, Kaplan GD, Maides SA. The development and validation of the health-related locus of control (HLC) scale. *J Consult Clin Psychol* 1976;44:580–585.

<sup>c</sup>Antonovsky A. *Unraveling the Mystery of Health*. San Francisco/London: Jossey-Bass, 1987:1–371.

<sup>d</sup>Sherbourne CD, Stewart AL. The MOS Social Support Survey. *Soc Sci Med* 1991;32:705–714.

<sup>e</sup>Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: Development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care* 2002;14:353–358.

<sup>f</sup>Sloan JA, Loprinzi CL, Kuross SA, et al. Randomized comparison of four tools measuring overall quality of life in patients with advanced cancer. *J Clin Oncol* 1998;16:3662–3673.

<sup>g</sup>Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *J Pers Assess* 1994;3:534–553.

TABLE 2. THE REVISED PATIENT-CENTERED TCI OUTCOMES PACKAGE, IMPLEMENTED IN 2003

<i>Measure</i>	<i>All of the measures can be administered at baseline, 6, 12, and 18 months with the exception of the Patient Satisfaction Survey</i>
1. SF-12 Mental Health Survey <sup>a</sup> Measures and interprets health status outcomes in both general and specific populations.	
2. Spitzer's Quality of Life UniScale <sup>b</sup> A single-item tool that asks patients to rate their quality of life during the past week.	
3. Patient Satisfaction Survey (Picker) <sup>c,d</sup> Eleven questions selected from the 40-item questionnaire to meet the TCI's needs. An additive score is calculated from questions that measure patient's satisfaction with clinic procedures, dissemination of information, relationships with the practitioners, and the physical surroundings.	
4. Numeric Pain Distress Scale Pain is a subjective sensation and, therefore, difficult to measure. A numerical pain scale allows a patient to describe the intensity of their discomfort in numbers ranging from 0 to 10.	
5. Energy Levels Scale Since coming to the _____, my energy level has: (a) Increased (b) stayed the same (c) decreased	
6. Control Preferences Scale <sup>24</sup> The Control Preferences Scale was developed to measure a construct that emerged from a grounded theory of how treatment decisions are made among people with life-threatening illnesses. The control preferences construct is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment."	
7. Social Support Questions Is there one person that you can count on? Yes/No From whom do you get your support (individuals/groups) Have you felt supported at _____? (a) Yes, completely (b) Yes, somewhat (c) No	
8. Stress Scale Are you more aware since coming to _____ of the impact stress has on your health? (a) Yes, completely (b) Yes, somewhat (c) No (d) Does not apply to me	

<sup>a</sup>Ref. 10.

<sup>b</sup>Sloan JA, Loprinzi CL, Kuross SA, et al. Randomized comparison of four tools measuring overall quality of life in patients with advanced cancer. *J Clin Oncol* 1998;16:3662–3673.

<sup>c</sup>Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: Development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care* 2002;14:353–358.

<sup>d</sup>Ref. 11.

pants receiving IHC. The intention of an interpretivist approach is to describe and interpret but not to develop a substantive theory. It is concerned with how people feel, respond, and give meaning to their experiences.

The second set of data was collected by the clinic nurse at the TCI. Initiated in January 2001, these goal-setting data were obtained during the intake session where patients discussed their reasons for enrolling in the Integrative Care Program and outlined the goals that they wished to achieve over the first 3 months in the program. While goals were individualized for each patient, the degree of goal attainment for each person was quantified in a follow-up session with the clinic nurse. Only the goals of patients with cancer were included in this analysis ( $n = 43$ ). We analyzed each of these goals by means of content analysis<sup>5</sup> to identify themes, rank their importance to each patient, and categorize the types of goals outlined by patients. It was anticipated that assessing this type of data would provide insight into how patients define their progress in IHC programs.

In contrast to quantitative analysis, the qualitative data cannot be summarized quantitatively, as participants did not respond to a standardized set of questions. Rather, personal and individualized narrative responses arising in nonstandardized interviews were analyzed in terms of emerging concepts, beliefs, and perceptions. Based on the strength and

extent of the comments, we ranked both perceived benefits and goals in order of importance.<sup>6</sup>

The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary (Calgary, Alberta, Canada).

## RESULTS

### *Part 1: Secondary analysis of interview data*

The objectives of the studies included in this secondary analysis were not related to identifying outcomes. However, the issue of patient outcomes and experiences using IHC was in the forefront for many patients throughout the interviews and focus groups. Six types of benefits experienced by participants were identified in the analysis: improved physical well-being, change in physiological indicators, improved emotional well-being, personal transformation, feeling connected, global state of well-being, and cure.

### *Improved physical well-being*

Most frequently, participants spoke of the improvements they had experienced in their physical state of well-being after using IHC. Improvements included alleviation of phys-

TABLE 3. DATA SOURCES USED IN THE SECONDARY ANALYSIS

<i>Name of study</i>	<i>Number/type of interview</i>	<i>Number of participants</i>
<i>Part 1</i>		
When Complementary Turns Alternative: Exploring Why Cancer Patients Forgo Conventional Treatment <sup>a,b</sup>	3 Focus Groups 12 in-depth, semistructured interviews	22
Assessing the Meaning of Evidence in Cancer Patients' Evaluation of Complementary and Alternative Medicine <sup>c</sup>	19 in-depth, semistructured interviews	19
Transformational Experiences Among Cancer Patients Seeking IHC <sup>d</sup>	11 in-depth, semistructured interviews	11
<i>Part 2</i>		
Goal Setting with Clinic Nurse, Tzu Chi Institute	Intake interview and 3-month follow-up interview	43

IHC = integrative health care.

<sup>a</sup>White MA, Verhoef MJ. Decision-making control: Why men decline treatment for prostate cancer. *Integr Cancer Ther* 2003;2:217–224.

<sup>b</sup>Verhoef MJ, White MA. Factors in making the decision to forgo conventional cancer treatment. *Practive* 2002;10:207–210.

<sup>c</sup>Verhoef MJ, Mulkins AL, Oneschuk D, et al. assessing the meaning of evidence in cancer patients' evaluation of complementary and alternative medicine (unpublished).

<sup>d</sup>Ref. 8.

ical symptoms, such as diminished pain, night sweats, and nausea. Participants generally attributed a specific intervention, such as a massage or taking a natural health product, to this change in health status. For many, IHC provided relief from their pain, leading to decreased dependence on pain medication, increased mobility, and a resulting improved quality of life:

So benefitwise, the pot makes my body feel a lot better, stops the night sweats, stops the aches and pains.

#### *Change in physiological indicators*

Participants described positive changes in both subjective and objective physiological outcomes. Increased energy and a boost in immune response were commonly cited subjective benefits, based on personal perception that participants identified after using IHC:

Strengthening my immune system. I believe that is where it's at . . . multi-immune and moducare. Those are the only supplements I take right now . . . I can feel colds coming on but they just pass through me and go on . . . I am just healthy.

Others made direct connections between IHC and more objective, physiological changes that had clear parameters, such as lowered PSA and improved body weight:

So I started out on the prostaflil and I have been on it about 3 months now and about a month ago I wanted to see if the prostaflil was working. My PSA had gone up to 5.8 and I started the prostaflil and a month later I had a PSA again and it had gone down to 5.5 so I knew it was working.

This degree of change in a PSA may not have clinical meaning in the absence of a continuing trend or can be a function of the laboratory assay. However, this patient was not aware of the lack of clinical significance and was buoyed by this change in PSA levels.

#### *Improved emotional well-being*

Participants found that using IHC had a beneficial effect on their emotional well-being. Some participants felt that IHC helped them to achieve a heightened sense of general well-being, a greater sense of control over their health, feelings of optimism, and lessened anxiety. For many patients, various aspects of IHC helped people cope with the stress of their illness more effectively. It slowed racing thoughts and worries, helping patients to reconnect with their bodies:

It is sort of an intangible but if you felt crappy coming in and walk away from your session feeling good, that is an intangible because it is not something that you can measure, they can't hook you up to electrodes,

there is not a weight difference. But the result is that you walked away feeling better. Mentally. So if you went in depressed and you come away happy, I think that is a benefit. You can't package it but it is a benefit.

Some participants recognized that these benefits were related to several of the principles of IHC, such as the emphasis on patient participation and individual responsibility, as well as the holistic aspect of the treatments. Additionally, individuals recognized that having a more active role in their health care decisions gave them a sense of control over their health:

IHC also allows you more control over your health. Because there are no barriers, you can do anything you want if you have the time and resources to do it. Because you are making decisions about how you want to live your life and hopefully you will respond to that.

### *Personal transformation*

Inner growth was also recognized as a benefit from using IHC. Individuals felt that IHC helped them to heal themselves, to gain a sense of purpose in life, find peace of mind, and to become more resilient, as well as provide an emotional outlet for them. Participants found that mind/body therapies were especially fundamental in facilitating this process:

I am changed and so the way I do things in my life is different. My whole pace has slowed down, so how I organize my day is different, so then my relationships with the people around me are different. I am more present in my life. Overall, I guess I just really, I feel different, I even think I look different. This has been a very profound and wonderful experience for me.

### *Feeling connected*

Relating to others at the IHC clinic and resonating with the experiences of other patients and practitioners often facilitated and intensified a person's inner work. Patients at the clinics formed strong and intimate bonds with other patients and practitioners that was attributed to an atmosphere of openness and willingness of these individuals to share on a deep emotional level. Listening to the stories of others sometimes allowed patients to access similar emotions in themselves and resonate with their feelings or experiences.

The power of working with others who have been where I have been was incredible. Hearing people's stories and how they deal with things . . . connecting with them I can see that I am not alone . . . everybody has their ups and downs and that everyone feels scared and alone. I realized it is okay to feel these things and

it is completely normal to feel this way. That brings me comfort knowing this.

### *Global sense of well-being*

In addition to personal transformation, participants felt that IHC was integral in helping them to experience more global shifts in their well-being. Participants began to live their lives more fully, which included engaging more socially, striving to reach personal goals, and trying new activities. IHC had helped them to focus on the more holistic aspects of their lives, the bigger picture. Their "living" began to feel more full, more meaningful, and more conscious:

I traveled this year. I wanted to get to Thailand and also to visit some family. I had things that I wanted to do. I realized this while at the Tzu Chi, so I set my sights high and pushed myself to travel. I had a wonderful time. I am no longer on a fast track, I am savoring life now, taking it all in . . . trying things I would have never dreamed of trying.

### *Cure*

Lastly, participants attributed their IHC use as a reason why they have remained "cancer free" and have not experienced a cancer recurrence or metastasis. This was certainly the desired outcome for many of the participants:

After 6 months through visualization I could see that the cancer was gone . . . I know I am healed. The PSA will show that it is completely gone. They thought I was crazy, and I believe my doctor was later discussing my case with other specialists around the country because of my remarkable recovery . . . To this day, I continue to have a clean bill of health.

Interestingly, this patient's PSA did return to zero and remains there.

### *Part 2: Content analysis of goal setting data*

Patients' treatment goals captured the desires, expectations, and motivations of patients enrolling in an IHC program. Assessing goals was helpful in identifying priority areas of outcomes that people seeking IHC deemed to be the most important and meaningful in their lives. The top five most commonly cited goals of cancer patients attending the TCI were: (1) to improve state of being, (2) to be cancer free, (3) to have more energy, (4) to manage pain more effectively, and (5) to return to active living.

### *State of being*

Goals in which patients aimed at feeling "more relaxed and less anxious," "optimistic and hopeful about life," and

“to learn to listen my inner voice tell me when to slow down” were categorized under “state of being.” These goals capture how people are in the present moment, their way of being with others (accepting and assertive), as well with themselves (peaceful and aware). These goals focused on mental and spiritual dimensions of the person rather than the physical.

### *Cure*

The second most common goal for individuals enrolling in the TCI program was to be “cancer free” and “to cure myself of this disease.” Patients specified that they hoped to learn techniques and health-promoting behaviors, such as diet, exercise, and relaxation to prevent recurrence.

### *To have more energy*

Cancer patients coming to the TCI often reported feeling drained and low on energy. Many hoped that the IHC program would specifically help to improve this. Their goals were to “feel rested and have some zip back” and “to feel like I have the energy to deal with the different issues in my life.”

### *Pain management*

The pain associated with a cancer diagnosis was debilitating for many of the patients. Many of the patients’ main motivations for enrolling at the TCI were to find some relief from their pain “to cut down on my pain meds” and “to have a day not dominated by pain.”

### *Return to active living*

Individuals were enrolling in the TCI with the hope of enhancing the goodness and meaning of their lives, which included their happiness. For example, individuals aimed to resume daily activities, such as “to help out again in my son’s classroom” or to be able to start doing activities for pleasure and “to really step back and enjoy my life.”

The types of goals identified here confirm the themes generated in the secondary qualitative analysis.

## DISCUSSION

Individuals seeking treatment and care at IHC clinics quite often struggled with multiple health problems, significant stresses, and relatively low quality of life. Through our experiences at the TCI, we were aware that meaningful outcomes for patients living with these complex conditions cannot be captured in simple black and white terms. Patients’ outcomes cannot be seen as separate from their lives, their experiences, their unique context, and the meaning they give to their healing process. Because the philosophy behind IHC

was to optimize patients’ vitality and wellness regardless of their current state of health, and to encourage patients to strive for realistic positive health changes, it is paramount that the way in which outcomes data are collected and utilized addresses patients’ needs and concerns as defined by them. However, in order to be useful in research, this should be done in such a way that, ultimately, quantification is possible.

### *Dimensions of outcome measures for IHC*

There is much agreement as to what outcomes should be measured, both theoretically and as emerging from patient experiences. The outcomes identified in our qualitative analyses show considerable overlap with those identified by Miller et al.<sup>7</sup> who have specified six domains of outcomes in their guidelines for “Assessing the Impact of Healing Relationships in Clinical Medicine.” These domains include: (1) measurable change in physiologic parameter, (2) symptom resolution, (3) cure, (4) improved sense of well-being, (5) movement toward wholeness, and (6) enhanced relationships. This suggests that healing relationships are an important part of IHC. The last domain, enhanced relationships, is similar to feeling connected. Healing relationships are not only mentioned as an outcome but also as an enabler of optimal healing. In other studies related to TCI, and to other IHCs, we also found that enhanced relationships are a major benefit often experienced by individuals accessing IHC.<sup>8,9</sup>

Benefits such as improved emotional well-being, personal transformation, feeling connected, and holistic sense of well-being demonstrate that the process of healing must be included as a critical element for evaluation as it focuses on how and why healing occurs. At the TCI, we found that the nature of this research required qualitative methods as we were assessing a very complex set of variables, such as motivation, patient-practitioner relationship, philosophical alignment, and self-awareness. Several existing outcomes scales, such as the SF-36<sup>10</sup> and the MYMOP,<sup>11</sup> address elements of these changes, but not in an integrated fashion, and they may miss changes in unexpected domains over time.

To illustrate this issue, Brazier et al.<sup>12</sup> found several significant outcomes following a randomized, controlled trial (RCT) of a mind/body intervention for patients living with HIV/AIDS. The questionnaires, selected to evaluate patient outcomes in this mixed-methods design, assessed standardized conventional benchmarks of well-being for emotional, mental, physical, and behavioral states. The quantitative findings documented minimal improvement in quality of life and an increase in the number of stressors and the impact of these stressors on one’s life for those in the intervention group. However, in the qualitative component, participants described a personal growth process that they felt was moving them toward a greater state of well-being. This growth

process did not always feel comfortable and, therefore, quantitative outcome measures may not have shown much improvement. Combining both quantitative and qualitative sources of data provides evidence of positive impacts on well-being for participants, in addition to illustrating the complexity in how these effects are experienced and sustained over time.

### *Cooperative inquiry*

Because the patients' perspective is crucial in understanding the process and outcomes of intentional self-healing, a participatory approach to research is recommended. Cooperative inquiry is a form of participatory, person-centered inquiry that does research with people but not on or about them.<sup>13</sup> As with the goal-setting exercise at the TCI, it requires patients to be coinquirers (with health coach or a practitioner) who can help articulate their reality. This approach to outcomes evaluation not only helps patients evaluate themselves and IHC programs but improves practice and fosters self-determination, using a form of self-evaluation and reflection.

### *Selecting optimal outcome measures*

Several instruments that address the outcomes identified in our analyses are available. However, it is critical to determine the appropriateness of outcome measures as they may vary depending on the intended uses and applications of the data and to take into account the amount of time and energy required by those to whom the outcome measures will be administered. In addition, when developing an outcomes package, researchers must keep in mind the purpose of the treatment and the setting for the treatment. Table 4 presents a list of such properties to consider when designing a comprehensive outcomes package for the assessment of IHC.

Focus groups that were conducted with TCI patients to solicit feedback on the direction of the Institute, revealed that many felt as though the questionnaires failed to capture their true experiences at the TCI. Patients also disliked the amount of paperwork required of them and the lack of interaction with the research staff. As indicated before, based on this feedback as well as the clinical staff and researchers' experience, we developed a more parsimonious set of patient-related outcomes measures, which was implemented in 2003 (Table 2). While references in Table 2 refer to the validity and reliability of a number of scales, no information is available on the validity and reliability of the energy levels scale, social support questions, and stress scale. These items were included in the outcomes package because they arose from clinical practice, addressed many issues relevant to integrative care, and appeared to have content validity. Although this early package met many of the criteria presented in Table 4, the package was by no means ideal, as it did not address key issues such as patient-practitioner rela-

TABLE 4. GUIDELINES FOR SELECTING SUITABLE TOOLS FOR PATIENT-CENTERED OUTCOMES EVALUATION

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An optimal outcomes package:

1. Is consistent with the conceptual framework (philosophy and practice) of the treatment
2. Is relevant (meaningful) for those receiving the treatment
3. Is psychometrically sound (reliable, valid, responsive, interpretable, sensitive to burden, language- and culture-specific)
4. Includes subjective and objective measures
5. Contains measures that are widely used (allowing comparisons)
6. Is comprehensive/multidimensional
7. Is patient-centered versus disease- mechanism-specific
8. Assesses wellness levels rather than having a disease orientation
9. Is useful to both patients and practitioners
10. Is sensitive to change
11. Covers specific and nonspecific effects (e.g., patient-practitioner relationship)
12. Contains individualized elements
13. Explores transformative changes
14. Is credible to conventional medicine
15. Includes global change in lived experience

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tionships, transformative change, and global change in lived experience. At that time, the literature only began to discuss such measures. Thus, we were not able to incorporate instruments included in the more recent literature, such as Bell et al.'s<sup>14</sup> global well-being outcomes rating scale or any of the potential instruments Quinn et al.<sup>15</sup> present, to measure outcomes of healing relationships in adult populations.

While an outcomes package should contain measures that are tailored to the needs of the organization and its patients, the following points may provide some guidance for package development. A wide range of patient-centered outcomes related to IHC should be captured in the form of: (1) qualitative interviews, (2) participatory outcomes such as goal setting/attainment, (3) quantitative surveys, (4) physician-ordered testing, and (5) objective measures of change in well-being.

A series of open-ended questions focusing on the patients' overall experience in an IHC program should be posed to each patient during an interview with the clinic nurse, health coach, or researcher at 6-, 12-, and 18-month time points. These questions should focus on the patients' overall "experience" in the program, satisfaction working with the practitioner team, sense of well-being, and changes in self-awareness.

Participatory outcomes such as individual goal setting should be initiated during a patient's initial intake session with the clinic nurse or health coach. Together, they should outline the goals that the patient hopes to achieve within their first 6 months in the program. Follow-up on the initial goals should be documented at the same time as the qualitative interviews.

Ideally, quantitative outcome measures should be completed in a survey format at baseline, 6, 12, and 18 months into a patient's program. In order to accurately detect changes in physiological indicators, physician-ordered testing and follow-up of various physiological outcomes (e.g., PSA) may be documented in the patient's chart and health history form. Lastly, Walach et al.<sup>16</sup> recommends exploring outcome measures that give a clear indication of improved well-being, such as number of work days lost, the reasons for this absenteeism, and health care utilization patterns.

Outcomes research is a valuable tool in evaluating IHC. While it is not as rigorous as randomized, controlled trials, it allows collecting a wide range of quantitative and qualitative data. A more participatory, patient-driven approach to outcomes research will allow everyone to better understand all components of the system of care in relation to the patient experience. More specifically, the addition of qualitative methods will help us to understand the process of the intervention, the context, and the meaning of the intervention for the patient.<sup>17</sup> The following quote illustrates why it is important to go beyond conventional measures in order to capture the more individualized transformational outcomes:

The TCI has built a healing community like no other. The dedication, positive loving attitude, and hard work have created an oasis of peace, a place where healing can blossom, a place where people with illnesses have become partners in their own health process, a place of wholeness. You have given us hope, where others only gave us numbers. You have given us back our lives.

We often encountered situations at the TCI where questions would arise out of practice for which the literature did not have the answers. This was the reality of operating in a new model of care and working with an immature knowledge base. Ideally, outcome measures can be incorporated into an in-house research/practice cycle that allows for continual evidence-based evaluation of the IHC model. In addition, information obtained from this process can realistically be used to implement change by administrators and practitioners to identify opportunities that will improve the quality of care for patients, as well as to provide administrators and practitioners with data to evaluate and strengthen their practice.

## CONCLUSIONS

Studies evaluating IHC need to assess change in terms of outcomes that are meaningful to the patients and fit appropriately with their life experiences. A wide range of outcomes is needed to assess the impact of IHC, especially those that focus on the process of personal transformation.

Future research is required to determine what an optimal outcomes package will look like in a variety of IHC settings.

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Address correspondence to:  
*Marja Verhoef, Ph.D.*  
*Department of Community Health Sciences*  
*University of Calgary*  
*3330 Hospital Drive NW*  
*Calgary, Alberta T2N 4N1*  
*Canada*

*E-mail: mverhoef@ucalgary.ca*