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Looking Beyond the Barriers: Practical and Symbolic Factors Associated with Disclosure of Complementary and Alternative Medicine (CAM) Use

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Abstract

Introduction: Research on disclosure of CAM use to physicians has focused more on barriers to disclosure than factors that promote disclosure. The purpose of this study was to test a new conceptual model of CAM disclosure which posits that disclosure of CAM use is motivated by both practical (positive CAM outcomes) and symbolic (sense of control, quality of the CAM provider relationship) factors that arise from the CAM treatment experience.

Methods: Two general medical samples provider-based CAM consumers, undergraduates (N = 226) and community-dwelling adults (N = 128), completed a survey about their CAM use and disclosure, health-related control, CAM patient-centered care, and CAM outcomes.

Results: Disclosure rates were 65% among students and 69% among the community adults. Univariate analyses revealed that disclosure of CAM use was associated with the symbolic factor provider patient-centered care in both samples, and perceived control over health in the student sample. In both samples positive CAM outcomes were associated with CAM disclosure. The multivariate logistic regression revealed that students who disclosed CAM use were more likely to report higher perceived control over health (OR = 1.5), patient-centered care (OR = 1.7), and positive behavioural CAM outcomes (OR = 1.4). However, the multivariate results for the community sample were non-significant.

Conclusions: The findings suggest that the benefits consumers experience from CAM treatments (practical factors) as well as the meaning of disclosing CAM use (symbolic factors) are associated with CAM disclosure, and underscore the importance of the patient-CAM provider relationship for promoting client initiated coordination of care.

Introduction

Research highlighting the increased use of complementary and alternative medicine (CAM) in recent years and that CAM is used predominantly to complement rather than replace conventional care [1-3] underscores the importance of CAM use being disclosed to conventional care providers. Indeed disclosure of CAM use is critical for coordination of care and minimizing treatment conflicts [4]. However, estimates of CAM use disclosure to physicians vary widely depending on the population, but in general can be low ranging from 12 to 53 percent in oncology patients [5,6], 36 percent in HIV patients [7], and 21 to 71 percent in general medical populations [8,9]. Successful co-ordination of care depends in part upon consumers playing an active role in facilitating communication between their different care providers [10]. Understanding the factors that facilitate disclosure of CAM use can therefore have multiple benefits for patient care.

Much of the research on CAM disclosure has focused on the barriers to CAM disclosure and the reasons patients have for not disclosing their CAM use rather than on the factors that may promote disclosure. The sociodemographic factors associated with non-disclosure include lower education [12], younger age [7], and gender [5,11], although the findings for the latter factor are inconsistent. Among the reasons for not disclosing CAM use noted in current research, perceiving that physicians will disapprove or react negatively to CAM use [12-15], and that disclosing CAM use wasn't important for their care [13-17], figure prominently.

Understanding CAM Disclosure

This study moves from a perspective that highlights the barriers to disclosing CAM use to one that focuses on how to promote CAM disclosure. TFew studies have examined factors associated with disclosure as most have focused instead on those linked to non-disclosure. For example, several studies have noted that the quality of the relationship with one's conventional

care provider and satisfaction with this care promotes disclosure of CAM [7,9,18]. However, no studies to date have investigated if and how the quality of CAM care may be associated with CAM disclosure. This gap is rather striking especially given that CAM disclosure tends to be higher for provider-based CAM than for self-care CAM [9,18], and that CAM care quality and satisfaction are important determinants of ongoing provider-based CAM use [2,19,20].

Conceptually, CAM disclosure may be best understood from a consumerist perspective that views disclosure as part of a collection of CAM-related behaviours reflecting a commitment to using CAM as a health-care option. A recently proposed model of CAM commitment based on a model of brand commitment from consumer psychology [21] and extant empirical research on continued CAM use, suggests that CAM can be viewed as a particular "brand" of health care that the consumer chooses [22]. From this perspective commitment to CAM is a psychological state with observable behavioral indicators including adherence to CAM provider recommendations and disclosure of CAM use to family, friends, and conventional health-care providers [22]. According to this model, CAM commitment develops from two types of positive experiences with the CAM brand: 1) a functional route associated with utilitarian needs and motivations that are reflected through positive CAM physical, psychological, and behavioral outcomes, satisfaction with CAM, and trust in the CAM provider and treatments, and 2) a symbolic route which involves a perceived "fit" between the consumer's values and the brand. Consistent with a systematic review of beliefs associated with CAM use [23], symbolic factors include beliefs about control over health, participation in health-care decisions, a holistic view of health, an emphasis on individualized treatment, and a desire for natural, non-invasive treatments. Together these utilitarian and symbolic values give rise to CAM commitment which is reflected in part in discussing and disclosure of CAM use to others including conventional

health-care providers. Analyses of data from a large sample of CAM users provided preliminary support for this model [22]. Accordingly, experiencing positive CAM outcomes (practical factors), and viewing CAM disclosure as a meaningful act that reflects taking control over one's health and feeling supported by one's CAM provider (symbolic factors), should predict disclosure of CAM use to one's conventional care provider.

Qualitative and quantitative research on related topics provides some support for these propositions. Given that research indicates that fear of negative reactions from physicians about CAM use discourages CAM disclosure [12-15], then having experienced positive outcomes from CAM may encourage disclosing CAM use because it demonstrates the practical value of CAM for dealing with symptoms and other health-related issues. With respect to symbolic values, there is evidence that health-care consumers view coordination of care among different health-care providers as a meaningful act[10]. Feeling empowered and supported by CAM providers is associated with engaging in health-promoting behaviours [24]. Thus, disclosing CAM use may similarly reflect feeling empowered to act on behalf of one's own health. With respect to taking control over one's health, there is also evidence that disclosure is associated with engaging in disease self-management behaviours [7].

The Current Study

The aim of this study was to examine the factors associated with CAM disclosure using a novel conceptual framework that highlights the practical and symbolic value of CAM use. Specifically, this study tested three practical and three symbolic factors with respect to CAM disclosure. The choice of factors to test was driven in part by the availability of existing, well-validated measures to assess appropriate content domains within the model, as well as the conceptual reasons outlined previously. The practical factors included all three positive CAM

outcomes categories – physical, psychological, and behavioral outcomes. The symbolic factors included perceived control over health operationalized as health-related mastery, participation in health-care decisions as assessed by perceived provider support, and an emphasis on individualized treatment assessed as patient-centered care.

It was expected that those who disclosed their provider-based CAM use to their physician would report greater experience of positive symptom-related and health behaviour outcomes from CAM treatment (practical factors), and higher health-related control and feelings of being supported and receiving individualized, whole person treatment by CAM providers (symbolic factors). Because much of the research on CAM disclosure has been conducted with illness populations whose decisions to disclose may vary depending on illness-specific needs, this model was tested with two general medical populations, community adults and undergraduate students who would be expected to have lower rates of chronic health conditions. To date there has been only one other study that has used a theoretical framework for understanding CAM disclosure [9]. However, in that study the quality of conventional care rather than the quality of CAM care was examined as a potential predictor of disclosure, and the data analyzed was 12 years old [9]. Given that research has demonstrated that the reasons for CAM related behaviours can change significantly within a ten year period [25], examining the reasons for disclosure using more recent data is warranted.

Method

Participants and Procedure

Following clearance from the university research ethics board, two samples – adults from the community, and undergraduate students - were recruited to participate in a study on perceptions of provider-based CAM use. Only current CAM users were invited to participate.

Recruitment of community participants involved placing notices in the community, and on web pages advertising psychological research. Student participants were recruited from the University of Windsor, a mid-sized university in Southwestern Ontario, Canada via notices placed on a university participant pool web page. A total of 1,378 students registered for the participant pool, and of these 353 qualified for the study as they were current users of provider-based CAM. From those who met the inclusion criteria, 262 agreed to participate in the study. The study notices provided a link to a dedicated web page for each sample which directed participants to the online survey housed on a secure university server. Participants indicated their consent to participate in the study by clicking an "I agree" button on the online consent form. Community participants were given the option to enter a draw for a certificate to an online bookstore, and student participants were given course credit for their participation.

Measures

Both samples completed identical surveys which included questions about demographic information and their CAM use in the previous six months, and measures of practical (perceived health-related outcomes from CAM use), and symbolic (health-related mastery, provider support, and patent-centered care) factors for CAM disclosure.

CAM Use

Participants reported whether they had visited a chiropractor, homeopath, naturopath, massage therapist, acupuncturist, reflexologist, reiki practitioner, or other CAM provider in the previous six months, and were asked to indicate who of these practitioners they considered to be their primary CAM provider. They also answered questions about whether they used CAM to supplement or replace conventional medicine, how long they had been using CAM, and whether they had disclosed their CAM use to their regular physician.

Practical Factors

Symptom change. Changes in four areas reflecting physical (sleep and energy level) and psychological outcomes (mood and concentration or focus), for better or worse, as a result of CAM treatment was assessed with a previously validated [26] 4-item scale with response options ranging from 1 (*much better than before*) to 5 (*much worse than before*). To better understand the nature of the symptom changes associated with CAM disclosure each item was analyzed separately.

Health behaviour change. Changes in health behaviours as a result of CAM use were assessed with five items developed and previously validated with CAM consumers [19,24,26]. Participants indicated whether they improved their diet, achieved a healthier weight, quit smoking, reduced their alcohol consumption, or increased their exercise on a dichotomous yes/no scale. Items were summed to create an overall behaviour change index. The reliability analysis indicated acceptable reliability in both the adult (Cronbach's alpha = .69) and student samples (Cronbach's alpha = .72).

Symbolic Factors

Health-related mastery. Perceptions of control over health were measured with the 8-item health mastery subscale from the Control Beliefs Inventory (CBI) [27], a well-validated self-report measure of perceived control over health that has been used previously with CAM consumers [28]. This subscale assesses feelings of competence and confidence in being able to carry out actions important for maintaining and taking care of one's health. Items are rated on a six-point Likert-type scale with response options ranging from 1 (*strongly disagree*) to 6 (*strongly agree*), and averaged with higher scores indicating greater health-related mastery.

Internal consistency of the scale was good in both the adult (Cronbach's alpha = .83) and student samples (Cronbach's alpha = .84).

Patient-centered care. Perceptions of receiving personalized, patient-centered care from the primary CAM provider were assessed with a 10-item previously validated patient-centered care scale [19,24]. Respondents indicated their agreement with statements, such as "The treatment is individualized for me at each session" and "My therapist receives feedback from my body that guides treatment" using a 5-point scale from "strongly disagree" to "strongly agree." The scale demonstrated very good internal consistency in both the adult (Cronbach's alpha = .95) and student samples (Cronbach's alpha = .94) in the current study.

Perceived provider support. Perceived support from the primary CAM provider was assessed with a 7-item previously validated scale [19,24] which included 7 statements, addressing ways in which patients may feel supported by their CAM provider. Similar to the patient-centered care scale, response options for this scale ranged from "strongly disagree" to "strongly agree." Reliability of the scale was very good in both the adult (Cronbach's alpha = .96) and student (Cronbach's alpha = .96) samples.

Data Analyses

T-tests were conducted on the symbolic and practical factors for each sample to assess univariate differences between the CAM disclosers and non-disclosers and to select the symbolic and practical factors to enter into the regressions. To determine which factors were independently associated with CAM disclosure in each of the samples, a series of step-wise logistic regressions, with CAM disclosure group as the dichotomous dependent variable, were conducted with the significant symbolic and practical factors for each sample entered individually. In all analyses, demographic variables (age, sex) were entered in the first step, and

the predictor variables (symbolic and practical factors) in the next step. To assess which of the factors was the strongest indicator of CAM disclosure, a backward step-wise logistic regression was conducted with all significant symbolic and practical factors entered in the second step, and a threshold of $p < 0.05$ set for retention and $p = .06$ for removal. In addition, unadjusted logistic regressions were conducted for each variable entered into the stepwise regressions to show the univariate estimates of associations as a comparator to the multivariate analyses.

Results

Participant Characteristics

A total of 354 current CAM users (128 adults from the community and 226 undergraduate students) completed the online survey. The community participants were from a variety of locations around the world, with the majority located in the USAor Canada(see Table 1). Most were employed full time and had a university/college level education . In contrast, the majority of the student sample were employed part-time or not at all, and had at least some university education.. The two samples were similar in terms of ethnicity and sex (see Table 1). However, the community sample was more diverse in terms of nationality, employment status, and education level.

CAM use

The majority of participants in both the adult (54.4%) and student (27.2%) samples had been using CAM for over five years, most of the community adults (72.0%) and students (75.7%) used CAM to complement rather than replace conventional medicine. Figure 1 presents an overview of the types of provider-based CAM used in each of the samples. Among both groups, massage therapy was the most commonly used provider delivered CAM, followed by chiropractic. For the adult sample, the next most commonly used CAM were other CAM, acupuncture, naturopathy, and homeopathy. For the student sample, the next most commonly

used CAM were Traditional Chinese Medicine, naturopathy, and homeopathy.

CAM Disclosure – Practical and Symbolic Factors

Disclosure of CAM use was generally high, with 69.3 percent of the community adult sample and 64.6 percent of the student sample reporting that they told their family doctor or other physicians about their use of CAM. The *t*-tests of the practical and symbolic factors associated with CAM disclosure in the adult sample revealed that those who disclosed their CAM use scored significantly higher on two practical factors, improvements in sleep and energy levels, and one symbolic factor, perceived patient support, compared to those who did not disclose their CAM use (see Table 1). In the student sample, scoring higher on one practical factor, positive changes in health behaviours, and all three symbolic factors differentiated those who disclosed their CAM use from those who did not.

The results of the unadjusted logistic regression revealed that those who disclosed their CAM use were more likely to experience improvements in sleep (OR = 2.09, $p < .05$) and energy levels (OR = 1.90, $p < .05$). None of the unadjusted odds ratios for the other variables entered (age, sex, or patient-centered care) were significant. The multivariate logistic regression model for the practical and symbolic factors associated with CAM disclosure was non-significant, χ^2 (8) = 5.21, and explained very little variance in the CAM disclosure groups (pseudo $R^2 = .01$). As well, none of the factors entered were significant unique predictors of disclosing CAM use after controlling for age and sex.

In the student sample health-related mastery (OR = 1.55), perceived patient support (OR = 2.08), and positive change in health behaviours due to CAM (OR = 1.36) were significant in the unadjusted logistic regression analyses (see Table 2). For the multivariate logistic regression, the three significant factors from the unadjusted analyses were retained after the backward step-

wise removal procedure: health-related mastery (OR = 1.49), perceived patient support (OR = 1.71), and positive change in health behaviours due to CAM (OR = 1.44; see Table 2). Those who disclosed their CAM use were more likely to score high on all three factors. The final model including these factors and the demographic variables explained 15.4 percent of the variance in CAM disclosure.

Discussion

This study examined CAM disclosure from the perspective of a new conceptual model that highlights the role of practical and symbolic factors for CAM consumers. Overall, the results provided preliminary support for the model by demonstrating that both practical and symbolic factors were associated with disclosing CAM use to physicians in one of the two general medical samples of CAM consumers. When the practical and symbolic factors were tested individually, consistent results were found only for provider patient-centered care, whereas the positive CAM outcomes associated with CAM disclosure differed across the two samples. When tested together with other model and socio-demographic factors, both practical and symbolic factors were unique predictors of CAM disclosure in the student sample, whereas these factors were not significant for the community adult sample. Overall though, the rates of disclosure in both samples were towards the high end of the rates for general medical populations [9].

Whereas previous research has demonstrated that the quality of the relationship with the physician is associated with CAM disclosure [9], this is the first study to find evidence that the quality of the relationship with the CAM provider is associated with CAM disclosure. According to the new model, experiencing provider support and patient-centered care from CAM providers motivates CAM disclosure in part because patients feel empowered to take a more active role in their health. Although this proposition was not directly tested in the current study,

it is consistent with previous research in which disclosing CAM use was associated with engaging in other proactive health behaviours [7]. Future research to verify these and other potential explanations for the symbolic value of CAM provider support is therefore needed.

The differences in the types of practical and symbolic factors associated with CAM disclosure in the two groups is noteworthy and may reflect the relative ages of the samples. For example, positive changes in symptoms due to CAM use may have been a more salient practical factor for CAM disclosure in the community adults simply because they were older and had more deficits in these symptoms to begin with. For students who were younger and likely more concerned with maintaining and promoting health than managing symptoms, the findings suggest that experiencing positive health behaviour changes have practical value for promoting CAM disclosure. That patient-centered care was the only significant symbolic factor for the community adults, whereas all three factors were significant for the students is intriguing. In particular the higher levels of perceived control over health associated with CAM disclosure in the student sample suggests that disclosing CAM use may be viewed as another way of taking control of one's health. This was not found for the community adult sample. One reason may be that the community adult sample was much smaller than the student sample. Indeed, the health-related control mean differences between the CAM discloser and non-discloser groups were nearly identical in both the samples. However, this difference only reached significance in the student sample suggesting that with a larger adult sample the test may have also been significant.

Limitations and Strengths

Although novel, the findings from the current study should be considered in the context of several limitations. The cross-sectional nature of the study precludes making any conclusions about causality, and therefore replication using more sophisticated methodology is necessary to confirm the proposed relationships suggested by the current findings. Although the surveys were

administered online there is considerable evidence that this mode of survey administration is comparable to traditional mode of administration [29]. The student sample was recruited through a formal and secure participation pool which, although non-random, increases the generalizability to other similar student populations which traditionally participate for bonus points. As noted, the smaller size of the community adult sample relative to the student sample may have contributed to the lack of significant findings for certain tests of the practical and symbolic factors as well as the overall multivariate analyses. As well, only positive CAM outcomes were tested from the list of practical factors suggested by the CAM commitment model, so it is unknown whether the other practical factors – satisfaction with CAM and trust in CAM provider and treatments – promote CAM disclosure. Similarly, the role of having holistic health beliefs in CAM disclosure needs to be explored. Because CAM disclosure is only one behavioral component of CAM commitment, it is likely that not all of the utilitarian and symbolic factors proposed by the model are linked to CAM disclosure; those that made the most sense conceptually were tested by the current study. Nonetheless, the current results which were inconsistent across the samples suggests that this may be the case. Differences in the age, nationality, employment status, and diversity of education levels of the two samples may also contribute to these inconsistences and should therefore be explored in future research as certain practical and symbolic factors may be more or less salient for CAM disclosure for samples with different socio-demographic profiles. Given that both samples were general medical samples it is also unknown whether the results from the current study will generalize to other populations and especially those who live with a chronic illness. Replication of these findings with larger and more diverse samples is necessary to more fully evaluate their generalizability and to assess the possible boundary conditions of the proposed model of CAM disclosure.

Current research indicates that rates of disclosure vary across different CAM modalities [30]. However, the reasons for CAM disclosure were examined across all CAM modalities in the current study. It is possible that certain practical and symbolic factors may be more or less salient for particular modalities. Accordingly future work should examine the role of practical and symbolic factors for explaining CAM disclosure stratified by CAM modalities.

Despite these limitations, the current study has a number of strengths worth noting. The introduction and testing of a new conceptual model of CAM disclosure makes an important contribution to the research on CAM disclosure, which has been largely atheoretical, by providing a framework to guide future research on the factors that may promote CAM disclosure. The testing of the model across two samples of CAM consumers with similar socio-demographic profiles is another strength that helps address issues of replicability of the findings.

Conclusions

In this study, perceiving positive outcomes as a result of CAM use, greater health-related control, and perceiving a quality CAM provider relationship were associated with disclosing CAM use to physicians. These findings suggest that the decision to disclose CAM use may be motivated by both practical and symbolic factors that arise from the CAM treatment experience and thus underscore the importance of the patient- CAM provider relationship for promoting client initiated coordination of care. Although physician initiation of communication about CAM use is also an important consideration for increasing disclosure rates [31], these findings indicate CAM providers can also play a role by empowering their clients to share their CAM experiences with their conventional care providers.

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