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The Chinese Life-Steps Program: A Cultural Adaptation of a Cognitive-Behavioral Intervention to Enhance HIV Medication Adherence

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Abstract

China is considered to be the new frontier of the global AIDS pandemic. Although effective treatment for HIV is becoming widely available in China, adherence to treatment remains a challenge. This study aimed to adapt an intervention promoting HIV-medication adherence—favorably evaluated in the West—for Chinese HIV-positive patients. The adaptation process was theory-driven and covered several key issues of cultural adaptation. We considered the importance of interpersonal relationships and family in China and cultural notions of health. Using an evidence-based treatment protocol originally designed for Western HIV-positive patients, we developed an 11-step Chinese Life-Steps program with an additional culture-specific intervention option. We describe in detail how the cultural elements were incorporated into the intervention and put into practice at each stage. Clinical considerations are also outlined and followed by two case examples that are provided to illustrate our application of the intervention. Finally, we discuss practical and research issues and limitations emerging from our field experiments in a HIV clinic in Beijing. The intervention was tailored to address both universal and culturally specific barriers to adherence and is readily applicable to generalized clinical settings. This evidence-based intervention provides a case example of the process of adapting behavioral interventions to culturally diverse communities with limited resources.

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Keywords

cultural adaptation; evidence-based practice; HIV/AIDS; Life-Steps

China is facing an expanding HIV/AIDS epidemic (Gill & Okie, 2007; Wang, 2007). With an official estimate of 740,000 HIV/AIDS cases and 60% of the those living with HIV under 29 years of age, China is considered the new frontier of the global AIDS pandemic (UNAIDS/ WHO, 2009).

HIV treatment became widely available in China only in 2003, when the federal government initiated the “Four Free and One Care” program providing free antiretroviral therapy (ART) treatment, counseling, testing, and other social services to individuals infected or affected by HIV/ AIDS. However, difficulties with treatment adherence (adherence is defined as ingestion of the correct dose of medication taken at the appropriate time and according to any special dietary instructions) have begun to surface (Zhang et al., 2007). Several reports have indicated that among patients on ART in 2003, only 75% to 80% were still refilling prescriptions for needed medication 6 months after beginning treatment (Zhang, Maria, Haberer, & Zhao, 2006; Zhang, Pan, Yu, Wen, & Zhao, 2005). Another study demonstrated that, among individuals on ART, 55% had missed at least one dose of ART in a 3-month period (Wang & Wu, 2007).

A growing body of literature has documented adherence levels and correlates in the West, but few studies have systematically explored ART adherence in China (Sabin et al., 2010; Wang et al., 2008). Although Chinese hospitals have invited Western experts to train practitioners to initiate and monitor ART therapy, only a handful of studies document the challenges encountered by Chinese people living with HIV/AIDS (PLWHA) in taking ART, let alone efforts to assist Chinese PLWHA in addressing these challenges.

Based on qualitative data from 28 Chinese PLWHA receiving care in Beijing, Starks and colleagues (2008) developed a model of optimal adherence that stipulated the need for four factors: (a) access to medication, (b) accurate knowledge of medication, (c) motivation to adhere to medication schedules, and (d) internal or external proximal cues to take medication (Starks et al., 2008). The model noted several major barriers to adherence, including financial difficulties, conflicting cultural beliefs on health and illness, and side effects of medication (Chen et al., 2009; Starks et al.). Another quantitative study identified 10 reasons for missing doses among Chinese PLWHA, including being away from home, forgetting, and feeling confused (Wang et al., 2008). Additional studies showed that while poor communication between physicians and patients may compromise adherence (Chen et al., 2007), social support can bolster adherence (Rao et al., in press; Fredriksen-Goldsen et al., 2011).

Meta-analyses of behavioral interventions to enhance adherence have demonstrated that they can be efficacious (Amico, Harman, & Johnson, 2006; Simoni et al., 2007). However, most have been developed and evaluated in the West, as have the majority of mental health interventions (Hofmann, 2006). Health-care providers must take account of cultural variation when disseminating promising interventions, and this includes reexamining underlying assumptions about behavior, pathology, and treatment (Bos, Schaalma, & Pryor, 2008; Li, Wang, Williams, & He, 2009).

We could locate only two published reports evaluating adherence interventions in China. Sabin and colleagues (2010) found that medical counseling based on feedback from electronic drug monitors (EDM) led to improved on-time adherence according to electronically monitored adherence in a sample of PLWHA in southwest China. Wang and

colleagues (2010) found that structured counseling along with telephone calls promoted self-reported ART adherence (Wang et al., 2010). However, neither study explicitly discussed how the intervention was designed to address both the universal and the culture--specific combinations of facilitators and barriers in China.

Given the complexity of ART adherence and the increasing challenges faced by Chinese HIV-positive patients, there is an urgent need to develop evidence-based interventions to promote medical adherence and prevent ART resistance among this population. The program we chose as having the most potential relevance in China was Safren and colleagues' Life-Steps (Safren, Otto, & Worth, 1999), which consists of 11 steps. In this program, barriers to adherence are identified, discussed, and addressed using cognitive behavioral therapy (CBT) strategies such as education, problem solving, and rehearsal techniques. The Life-Steps program has been proven to be efficacious in promoting ART adherence in the U.S. and in India (Safren et al., 2006; Safren et al., 1999; Safren et al., 2001). We previously reported on the promising findings of the adapted Life-Steps program in China (Simoni et al., 2010); in a preliminary randomized controlled trial ($N=70$), the intervention led to some improvement in self-reported and electronically measured adherence, but not biomarkers.

In this paper, we describe the process of cultural adaptation we used to modify the original Life-Steps Program and present the final adapted intervention, noting modifications we made based on the results of the pilot implementation project. We incorporate two case examples that illustrate the intervention.

Cultural Adaptation of the Intervention

Cultural adaptation should focus on two aspects of an intervention: content and procedures (Hwang, 2009; Lau, 2006). Culturally appropriate treatment content should address specific combinations of risks and protective factors present in the targeted population so the intervention can optimize coping capacity. Treatment procedures should be feasible and acceptable to the target community, in consideration of the local context. Conversely, a lack of social validity in treatment content and procedures may increase the probability that the treatment will be rejected by the community, regardless of its efficacy (Lau, 2006). We discuss the adaptation process in detail below, but for a summary, see Table 1.

During the adaptation process, the primary aspect of Chinese culture we considered was that of the familial-collectivist society, a society in which close-knit, highly structured kinship networks are the foundation of interpersonal relationships and interactions (Yang, 1995). Within this context, maintaining harmonious familial relationships, preserving the family's reputation, and showing reverence for authority often outweighs the pursuit of individual goals and autonomy. The cultural imperatives of China's familial-collectivist society have created both barriers and facilitators to ART adherence among Chinese HIV patients (Starks et al., 2008). Other reports have documented that these interpersonal relationships play critical roles in determining ART adherence (Chen et al., 2007, 2009, 2010; Fredriksen-Goldsen et al., 2011; Starks et al.). The second cultural aspect we considered was the Chinese view of human illness as being caused by a disruption in the natural balance of yin and yang. According to this view, ART is seen as an intrusive treatment that harms the body by interrupting its natural healing processes (Chen et al., 2009; Chen, Shiu, Simoni, & Zhao, 2011). Chinese HIV patients who hold this belief may be less willing to initiate their ART treatment and less likely to maintain optimal adherence (Chen et al., 2009, 2012). Given this context, the Chinese Life-Steps program aimed to address medical adherence issues by addressing individual barriers and by identifying and utilizing the strengths of Chinese culture as part of this process.

To increase the sensitivity of our intervention to the Chinese cultural context, we remodeled the Life-Steps program according to the conceptual model we developed for medical adherence among Chinese HIV-positive patients (Starks et al., 2008). First, given that most of the ART medications are covered by the “Four Free and One Care” program and free to patients, we found that PLWHAs’ access to medications is best ensured by regular visits to the clinic, and that improving the physician-patient relationship and enhancing medical communication is the best way to ensure that PLWHA *make* these visits. Second, psychoeducation about HIV, medications, and side effects, combined with a thorough introduction and discussion of their own regimens, can increase PLWHA’s knowledge about their medications. Third, we found that skillful use of PLWHA’s interpersonal relationships and involvement of a treatment partner can enhance motivation to adhere to medication schedules. Fourth, use of reminder strategies, such as setting alarms, can serve as the proximal cue to take medications. We did not seek to confront or attack participants’ cultural notions about health (notions like the yin-yang balance theory), so we did not force them to accept ART as a “health-protecting tool.” Instead, we helped facilitate the development of more balanced views about regimens among patients while helping them reconceptualize side effects as evidence of the effectiveness of ART. Finally, given our previous research finding that many Chinese PLWHA perceive a lack of personal control over their treatment (Chen et al., 2007), we decided to empower them by allowing them to freely choose their combination of interventions. Accordingly, we gave them a choice between receiving an alarm device or counseling, either individually or with a treatment adherence partner.

Two Chinese-fluent researchers, experienced in providing mental health services to Chinese PLWHA and familiar with cultural psychology, worked closely to adjust the intervention to the nuances of Chinese culture according to those cultural assumptions tested in our analysis. In addition, the content of the intervention was checked for feasibility and cultural relevance by experienced mental health practitioners in China. In order to optimize the social validity of the intervention, two factors were considered. The first factor was the type of intervention to be conducted. The second factor was the question of who would be trained as an interventionist. CBT, the foundation of the Life-Steps program, has been documented to be efficacious in the Chinese cultural context (Lin, 2001). Although it has not yet been applied to promote Chinese HIV-positive patients’ ART adherence, CBT has been demonstrated to successfully decrease Chinese PLWHAs’ distress and improve their quality of life (Molassiotis et al., 2002). Likewise, the principles and techniques unique to CBT are compatible with the core values of Chinese culture. For example, the didactic role played by therapist, present-oriented skills trainings, and written homework assignments correspond with three Chinese cultural tenets: respect for hierarchical power structure, pragmatism, and the Confucian emphasis on academic exercises and achievement (Foo & Kazantzis, 2007; Hodges & Oei, 2007).

As part of the adaptation, we opted to train nurses as interventionists for several reasons. First was the fact that nurses were the most available candidates. Psychobehavioral interventions have emerged in China only within the past two decades (Yu, Chou, Johnson, & Ward, 2010); thus, mental health providers, such as psychologists and social workers, are not yet widely available to the Chinese population. Second, due to on-site recruitment and payroll policies, it was not feasible to hire outside mental health practitioners to implement our intervention. Although nurses in China rarely provide counseling about patient treatment plans (Chen et al., 2010), there is reason to think they would do well to adopt this role more often. Chinese nurses spend the majority of their shifts in the wards and have in-depth understanding of the biopsychosocial condition of individual patients. Moreover, they are a widely available resource in China, have extensive knowledge about patient care, and often have more flexibility to carry out adherence counseling as compared to physicians. Studies have demonstrated that nurse counseling can enhance HIV medication adherence (Cook,

McCabe, Emiliozzi, & Pointer, 2009; Ramirez-Garcia & Cote, 2009; Williams et al., 2006). Although nurses were used in the current project, we believe that, with appropriate training, a wide array of health-care practitioners could successfully deliver the intervention as well.

The development of nurse counseling skills was a critical task ensuring both the quality and efficacy of our intervention (Chen et al., 2010). To build the nurse counselor's capacity and counseling skills, a research team from the University of Washington with experience in psychology, social work, and nursing conducted an intensive 40-hour training workshop. With two graduate-level trainers on site for 1 week, basic and advanced counseling skills were discussed, reviewed, and role-played with six nurse trainees from the research hospital. After completing the workshop, trainees were expected to do patient interventions in which psychosocial issues related to nonadherence and other HIV-related issues were identified and addressed. Case demonstration was utilized as an additional training tool in the workshop to familiarize trainees with the practices of the intervention. Ultimately, we learned that only one nurse would be available to provide the interventions, due to recruitment and payroll policies in China's public health-care system. We worked closely with the hospital administrators to identify the nurse interventionist who had the best fit with the research project regarding her mastery level of skills, willingness to participate, and other administrative concerns. After the nurse counselor was selected, parts of her clinical duties were shifted to colleagues to relieve her work burden during the study. Because the nurse counselor typically met two participants per week, she received supervisions every other week via telephone on how to discuss complicated situations as they emerged. The two trainers were also available through email when the nurse counselor needed immediate assistances.

The Chinese Life-Steps Program

Our final adapted version of the Chinese Life-Steps program consisted of 11 steps, with an additional (optional) component involving a patient-selected treatment adherence partner. The Chinese adaptation shares the same theoretical basis as the original program. Both programs offer problem-solving therapy, in which the overall task of taking medication is broken down into small steps. At each step, the nurse counselor and the participant identify barriers, explore potential solutions, make decisions, and practice skills necessary for action plans.

Step 1: Motivation and Engagement

The goal of the first step is to help motivate the patient's commitment to the program in order to facilitate increased engagement in the patient-provider relationship and thus allow the patient to feel more comfortable discussing issues related to adherence and to the disease itself during intervention sessions. This can be difficult at times, because modern psychobehavioral therapies have only emerged within the last two decades in China (Yu et al., 2010), and traditional cultural values emphasizing familial reputation as well as fears of "losing face" add additional stigma to the help-seeking process.

A good way to motivate and engage Chinese PLWHA in ART adherence is to discuss with them how adhering to a regular medication timetable will allow them to pursue what is personally and interpersonally significant to them. For example, the interventionist can explain how staying healthy by taking medication will allow people in treatment for HIV/AIDS to stay focused on the goals and activities they treasure most. Several studies have documented specific values and goals that are salient for Chinese patients in their efforts to maintain health (Chen et al., 2009; Chen et al., 2007; Starks et al., 2008). For Chinese patients in these studies, "living for others" and "being able to carry out familial obligations"

were important incentives for preserving health. Skillful use of these incentives can engage Chinese PLWHA more effectively in the program intervention.

Step 2: Interactive Psychoeducation

Accurate information is a critical prerequisite for healthy behaviors, and it is also a foundation of medical adherence. Therefore, the goal of this step was to ensure that Chinese patients obtained basic knowledge about ART adherence and HIV/AIDS. Due to a paucity of high-quality and culturally appropriate psychoeducational multimedia materials in China, a highly interactive psychoeducational curriculum was designed for the nurse counselor to deliver in the second step of the Chinese Life-Steps intervention. This interactive curriculum, provided in a flip-chart format, encourages patients to discuss the meaning of HIV medication and ART adherence. Using this approach, the nurse counselor could assess the participants' level of knowledge, address their particular needs, and utilize positive reinforcement to build knowledge while correcting misconceptions.

The psychoeducational material included two major components: basic knowledge and ART adherence information. Topics covered in the basic knowledge component included the mechanism of ART, viral replication and resistance, the meanings of CD4 and virus load, and issues related to medication sharing. Topics covered in ART adherence included the definition of adherence, factors that may lead to poor adherence, and consequences of good and poor adherence. Finally, the intervention emphasized the importance of using teamwork—including active partnerships with nurse counselors and family members—to achieve optimal medical adherence.

The nurse counselor also evaluated participants' attitudes toward various HIV treatments, including both Western medications and traditional Chinese herbal medicine (Chen et al., 2007). Some individuals were able to accommodate up-to-date knowledge about HIV, while others struggled to change their underlying cultural notions of health and illness. Authoritarian interventions to change cultural concepts were not appropriate for this population and might have led to the premature termination of participants. Hence, the ultimate goal was not to “foster the patient's perspective that the pills are health-protecting tools” (Safren et al., 1999, p. 335), as practiced in the original program, but rather to assist Chinese PLWHA to develop balanced views of ART within their cultural framework of health and illness. To achieve this goal, the nurse counselor talked about the risks and benefits of ART with patients, discussing preferences and outlining choices.

Step 3: Getting to Appointments

In this step, the goal was to establish with participants that proactive problem-solving can assist patients to consistently attend appointments with their health-care providers. Many Chinese PLWHAs travel from rural counties to metropolitan areas for ART (Chen et al., 2007; Starks et al., 2008), often to avoid acute HIV stigma in their hometowns (Starks et al., 2008) and because of their mistrust of local health-care providers (Chen et al., 2007). Transportation to appointments was often constrained by financial difficulties (Starks et al., 2008). For Chinese PLWHA in urban centers, a different set of factors inhibited appointment adherence. For example, in urban areas patients were more likely to miss appointments due to work schedule conflicts and child-care needs. Taken together, appointment attendance emerged as a significant barrier for many patients, regardless of residential status.

To increase the efficacy of treatment, nurse counselors could discuss and problem-solve barriers related to appointment adherence with all patients. To broach the topic of appointment adherence, the nurse counselor asked patients about the frequency of their

medical appointments and current modes of transportation. The nurse counselor then assisted patients to identify potential barriers and develop feasible strategies and back-up plans for their medical visits.

Step 4: Communication With Health-Care Providers

Studies have documented that the combined effects of the Chinese health-care system, dynamic interprofessional relationships, and collectivistic cultural assumptions have placed tremendous constraints on the provision of health services to Chinese PLWHA (Chen et al., 2010). Under the influence of Confucian thinking, which emphasizes reverence for authority (Tsai, 2005), Chinese PLWHA typically perceive their health-care providers, particularly physicians, as powerful authoritative figures (Chen et al., 2007). These factors together might prevent honest and open communication between patients and their health-care providers.

To overcome these barriers, cognitive reframing skills and role-plays were utilized to assist Chinese PLWHA to reconceptualize their relationships with health-care providers. Patients were encouraged to view health-care providers as working partners rather than formal authority figures, with the goal of making patients feel more comfortable discussing their needs and ART adherence difficulties with their providers. Note that in this step we did not encourage patients to challenge the authority of their health-care providers; rather, we encouraged them to participate in their own care. Because traditional Chinese culture emphasizes interpersonal harmony, a focus on confrontation with health-care providers could have resulted in the breakdown of doctor-patient relationships and would have actually led to worse adherence outcomes (Bakken et al., 2000; Holzemer et al., 1999).

Step 5: Introduction of the Patient's Regimen

Many Chinese patients did not fully understand their ART regimen at first, so this step of the program was designed to help patients learn the full names of their ART medications, exact dosing requirements, and any applicable dietary restrictions associated with them. The nurse counselor asked the patients to show their regimens and name their medications, using this as an opportunity to reinforce accurate responses and correct possible misconceptions about ART and adherence.

Step 6: Medication Scheduling, Sorting, and Storing

This step was designed to assist patients in incorporating a fixed medication schedule into their day-to-day routines. This was derived from research findings suggesting that Chinese PLWHA who successfully adhere to regimens are able to conceive of ART as a part of their daily life (Chen et al., 2007; Starks et al., 2008). To achieve this goal, pill-taking was broken down into three separate activities: creating a daily medication schedule, making adherence part of a daily routine, and reviewing the daily medication schedule.

First, the nurse counselors assisted the patients to design a workable medication schedule that fit the patient's daily routine. To enhance adherence to this time schedule, the nurse counselor assisted patients in sorting their ART pills both by time markers and the use of special containers, such as color/day-coded pillboxes. Then, in a strategy called cue-dosing, the nurse helped patients link pill-taking behavior to other behaviors that might co-occur (e.g., meals and favorite TV shows). The nurse counselor also asked individual participants to identify possible conflicts with other activities and to brainstorm possible solutions to address barriers to time adherence.

Second, the nurse counselor assisted patients to identify daily events or activities that could serve as triggers for medication taking. However, daily routines fluctuate, potentially

disrupting adherence; therefore, the nurse counselor encouraged patients to identify potential changes in their normal routine behaviors and assisted them in advance planning. Role-playing within different scenarios helped patients to develop and practice new strategies to maintain adherence in the event of alterations in routine. Finally, the nurse counselor reviewed daily medication schedules with patients. Both nurses and patients assessed the feasibility and manageability of time schedules and fine-tuned individual plans as needed.

Step 7: Reminder Strategies

In previous studies, many Chinese PLWHA utilized a mix of internal and external reminders—as proximal cues of action—to enhance ART adherence. Use of proximal cues of action was the most significant facilitator for ART adherence among Chinese PLWHA in addition to a strong desire to survive (Starks et al., 2008). In this step, the nurse counselor asked the patients to identify some possible reminder systems that could be tied in with their daily activities; things such as wrist watch and cell-phone alarms. The primary goal of this step was to explore and respect patients' preferences regarding the incorporation of reminders in their lives. The nurse counselor encouraged patients to use multiple strategies to remind them of dosing times, should the primary one fail.

Step 8: Coping With Side Effects

Side effects are a major barrier to ART adherence (Chen et al., 2009; Wang & Wu, 2007). In previous studies, many PLWHA perceived ART as “poisonous” or dangerous to their health (Chen et al., 2009). For these patients, many of whom subscribed to notions of traditional Chinese medicine, health could only be restored through a gentle rebalancing of the yin and yang forces in the human body. Therefore, ART was viewed not only as an effective treatment method but as an alien and harmful influence that could disrupt the harmonious balance between these two forces (Chen et al., 2009; Chen, Shiu, Simoni, & Zhao, 2011). The nurse counselor, cognizant of the impact these cultural beliefs about health could have on ART adherence, helped patients understand the components of the ART, thus resolving the conflict between patient health beliefs and adherence. Without trying to change the cultural health beliefs of patients, the nurse counselor re-conceptualized ART side effects as evidence of the effectiveness of the ART regimen. This in turn eased patient anxieties about potential treatment failure (Chen et al., 2009).

Many HIV-positive patients perceive a diminishing sense of control if they feel that ART is the only choice available: a choice they may associate with uncomfortable side effects and complicated medication schedules (Berg et al., 2004; Chen et al., 2009; Dunbar et al., 2003). Accordingly, involving the participants in their own treatment plans, particularly in regards to side effects, can increase their sense of control. In this intervention study, the nurse counselor discussed the possible side effects that could occur and possible symptom management for these side effects. The nurse counselor also explored strategies that participants had utilized to manage symptoms and offered additional symptom management options to consider in the future. Finally, the nurse counselor encouraged participants to discuss ART and its side effects with their health-care providers. To instill confidence, role-playing was practiced to prepare patients to discuss their side effects with health-care providers.

Step 9: Handling Slips

The goal of this step was to encourage the Chinese PLWHA to manage lapses in adherence and get back on track as soon as possible. The nurse counselor was trained to assist PLWHA to accept mistakes, acknowledge their experiences of “slips,” and alleviate their guilt over missed medication doses. The nurse counselor worked with patients to identify the major reasons for slips and assisted them to develop strategies to prevent these lapses in the future.

Step 10: Problem Solving for Additional Barriers to Adherence

The intervention program was designed to assist patients in overcoming commonly shared barriers to ART adherence. However, some barriers may not be covered by the Chinese Life-Steps; therefore, the goal of the tenth step was to address specific barriers unique to a patient's individual circumstances.

Each participant was asked to identify additional barriers to adherence in his or her day-to-day routine. Then, the patients were asked to evaluate the effectiveness of their current coping strategies to address barriers to adherence. Cognitive reframing and role-plays were used to develop alternative coping strategies to replace those that proved ineffective.

Step 11: Review

In order to reinforce key information and to facilitate the participants' mastery of the new tasks necessary for adherence, the nurse counselor reviewed each step with emphasis on the new knowledge, skills, and plans that had already been discussed and practiced in previous steps. The nurse counselor wrote down the key action items and gave them to patients. If a patient had limited literacy skills, the patient was asked to repeat the action items to the nurse before the conclusion of the session. Finally, homework was negotiated and assigned for the participant to practice in the home environment.

Utilization of Treatment Partners

To more effectively respond to barriers and facilitators to optimal adherence embedded in the Chinese cultural and social context, we made an important additional adaptation to the Life-Steps program. Given the familial nature of Chinese society, we invited the PLWHA in this study to select a treatment partner if they wished. It has been documented that treatment partners can provide support to enhance Chinese PLWHA's ART adherence, and further, that those who enjoy a higher level of social support on medications also have superior adherence (Fredriksen-Goldsen et al., 2011). Since most PLWHA have a primary family caregiver (Li, Lin, Wu, Lord, & Wu, 2008; Li et al., 2007), the nurse counselor invited patients to select a treatment partner (either a spouse, partner, other family member or friend who provided care and, ideally, lived with the patient) to participate in the intervention.

Among those patients who chose to involve a treatment partner, the nurse counselor delivered all the Life-Steps sessions to the dyad. In this intervention option, the nurse counselor worked with both the PLWHA and treatment partner to identify the facilitators and barriers to adherence and to develop an action plan. Together they brainstormed and explored creative and feasible ways in which the treatment partner could better assist the participant in taking ART medications. When appropriate, the nurse counselor provided training to the dyad to improve communication and conflict-resolution skills. Through role-plays, the participant and the treatment partner practiced communication and active problem-solving skills related to HIV and medication adherence. This modality utilized the interpersonal and dynamic relationship between the partners to motivate and engage both members in the intervention process.

Although the utilization of treatment partners is promising, it has its limits. Due to pervasive HIV stigma, several of the HIV-positive patients were not comfortable disclosing their HIV status to family members or other potential support persons, and access to an indigenous treatment partner was therefore not feasible. It's important to note that we did not actively encourage our participants to disclose their diagnosis to their family members. Although many obtained additional support from their family after disclosure, some did not. In fact, some even lost their family support, which is typical among newly disclosing Chinese PLWHA (Chen et al., 2010; Chen, Shiu, Simoni, Zhao, Bao, et al., 2011; Li et al., 2007). In

cases where disclosure is infeasible and support from family is not readily available, health-care providers must take an even more significant role in supporting Chinese PLWHA's adherence, as the providers may often be the only persons who are aware of the diagnosis (Chen et al., 2007).

Two Case Examples

In this section, two cases are presented to illustrate how Chinese Life-Steps can be applied in practice. Both cases involved combinations of various facilitators and barriers to medical adherence.

Case 1

The first case involved a 52-year-old heterosexual, married male who resided in Beijing with his wife and daughter and was relatively new to the ART treatment program. Since he had retired and his medication was free, he had no financial burden from the disease and could refill his prescriptions in a timely manner. His family had been informed of his HIV status, and they demonstrated acceptance of and support for the participant. Therefore, he did not need to hide his medications and took them openly. Although this participant enjoyed sufficient external support, he faced some internal barriers to adherence. First, although he was quite knowledgeable about basic medical concepts such as viral load and drug-resistance, he had little understanding about the mechanisms of his medications and possible side effects. He made several mistakes when recalling the names and functions of his medications and was unable to correctly sort his daily regimens. Second, when he attended his first session he was still new to ART and had not experienced any negative side effects. Nor did he evidence any anxiety about *possible* side effects. However, within 1 month, he started to experience rashes, nausea, and other uncomfortable symptoms. Unfortunately, because he had difficulty communicating with his health care provider about his side effects, he became increasingly anxious about both his side effects and his regimens. Although he had been using an alarm to remind himself of medications, ultimately he decided that it was inconvenient to use an alarm to cue himself, especially when he was not at home. As a consequence of these barriers, this participant had missed his medications several times in the second month.

In order to confront the barriers this participant encountered, the nurse counselor employed several strategies. First, accurate information about side effects was provided in the psychoeducation session (Step 2) to ensure the participant's comprehension about ART's side effects. Second, the nurse counselor reviewed medication names, functions, mechanisms, dosages, and side effects with the participant (Step 5). Third, under the supervision of the nurse counselor, the participant learned to sort his regimens according to his prescription and practiced sorting until he demonstrated mastery (Step 6). Fourth, to better facilitate this participant's communication with his health-care providers, the nurse counselor role-played with him so he could practice how to effectively convey his concerns over side effects to his health-care providers. Also, the nurse counselor explored his fear and anxiety regarding the ART side effects and brainstormed potential coping strategies to mitigate symptoms (Step 8). Finally, the participant learned to use his cell phone as his medication reminder/alarm clock as a way to avoid curiosity and inquiries from those in his social network who were unaware of his serostatus. As a result of this intervention, this participant did not miss any dose during the next month, as documented by electronic records.

Case 2

The second case involves a sero-discordant gay couple. The participant, recently diagnosed and new to ART, was a 29-year-old gay man who worked as hotel project manager. His partner was an HIV-negative, 40-year-old high school teacher. Due to the stigma attached to homosexuality in China, the couple did not reside in the same household but in separate homes in close proximity to each other. Because this participant obtained very little support from his family of origin, he relied primarily on the assistance provided by his partner, including financial aid, emotional support, and medication management reminders. Like many PLWHA in China, this man was also provided with free medication and experienced little difficulty accessing his prescriptions and treatments. Despite these external supports, however, this participant experienced other barriers, both internal and external, which affected his ability to establish an adherence routine. First, because the participant delayed seeking medical evaluation until he was highly symptomatic, his illness had already progressed to AIDS. He suffered from tremendous uncertainty and anxiety as he confronted his HIV status and was unsure about the effectiveness of the treatment regimens for someone in his advanced state of the disease. Second, this participant demonstrated limited medical comprehension of his illness and lacked basic knowledge regarding his prescriptions. Without much understanding of his regimens, he was unable to articulate the names, functions, and dosage of his medications in detail. Third, because of HIV stigma, the participant occasionally had to hide his medications when he had house guests. Finally, notwithstanding the assistance the participant received from his partner, the relationship between the two was stressful to the participant. It was revealed that due to miscommunication, the participant felt his partner was too intrusive and was micro-managing his life. As a consequence of these barriers, this participant was reluctant to start taking ART treatment even several weeks after having it prescribed. During the initial period of his treatment, he depended completely on his partner for adherence assistance, a factor that caused considerable distress to the participant.

Several strategies were developed and implemented to motivate this man to more readily engage in treatment. First, the nurse counselor reviewed with the participant basic knowledge about HIV and other related concepts, such as viral load and CD4 (Step 1). In this step, the nurse counselor also encouraged the participant to explore the anxiety caused by his illness, uncertainty about the nature of HIV, and treatment effectiveness. By carefully weighing the pros and cons of antiretroviral therapy, this participant reached a conclusion that taking ART was, overall, beneficial to him. Second, the nurse counselor introduced the medications in great detail, including names, functions, and dosages, among other information (Step 5). Third, the participant learned to sort his pills accordingly and store his medications in an appropriate place (Step 6). Fourth, the nurse counselor invited the participant and his partner to brainstorm potential solutions to assist the participant in taking his medications while house guests were present (Step 10). Fifth, the participant also learned to set an alarm to cue him to his medication schedule instead of relying on his partner for reminders (Step 7). Finally, the nurse counselor provided skills training to improve the quality of the couple's communication, as well as their overall relationship (Step 9). At the end of the intervention, the participant stated that his partner reminded him only two or three times a week and he felt more satisfied with his relationships because he can enjoy more personal space. He had taken charge of his medication and felt more control over his treatment, without losing needed support from his partner. Moreover, as the physical symptoms of AIDS diminished due to consistent adherence, this participant gained more faith in ART treatment. These positive changes reflected in his medical adherence. In the follow-up survey, the electronic records showed no lapse in received dosage.

Discussion

These two case studies exemplify the Chinese Life-Steps intervention's success in promoting or maintaining ART adherence among a group Chinese PLWHA. Moreover, as illustrated in another report, the intervention is highly feasible in China and can successfully promote or maintain ART adherence among a group Chinese PLWHA (Simoni, et al., 2010). During the post-intervention follow-ups, those who received the Chinese Life-Steps program were two times more likely to have 100% adherence to their regimens at 19 weeks.

Although we did not directly measure acceptability of the adapted intervention to our Chinese participants, the retention rates between the two intervention arms could still provide some hints about its acceptability. In the enhanced intervention arm, in which we provided the Chinese Life-steps program, all 35 participants completed the 25-week study. By contrast, in the regular care arm, where the participants did not receive our intervention, 6 participants prematurely terminated the study. (See Table 2 for a summary.) The Fisher's exact test showed significance at $p=0.01$ (<0.05), suggesting that there were significantly fewer dropouts in the enhanced intervention arm. If the adapted intervention had not been acceptable to Chinese participants, we would have expected a higher dropout rate among those who received it. On the contrary, the adapted intervention was not only acceptable to Chinese participants, but might also help to maintain the retention rate.

The Chinese adaptation of the Life-Steps program retains many viable components of the original intervention. However, it is distinguished from the original intervention in that it is tailored to address the unique combination of facilitators and barriers to adherence that is characteristic of Chinese culture. Comparisons between our Chinese Life-Steps program and the original intervention are summarized in Table 3, which shows treatment components that underwent significant adaptation (highlighted in bold) and relates the changed items to culturally specific factors among Chinese PLWHA. Those Life-Steps components that were not changed from the original reflect factors that we felt to be universal among PLWHA. These factors were incorporated into our conceptual model accordingly (see Starks et al., 2008).

Despite our initial successes, we are not advocating that this intervention alone can solve all the difficulties faced by Chinese PLWHA struggling to adhere to ART regimens. Institutional and cultural barriers related to medication and health-care access will likely always be a concern for this population, and a wide variety of innovative and collaborative solutions will be needed to address them. Psychological problems can interfere with ART adherence as well—problems such as depression and alcohol abuse—and these need much more attention in the future.

The interventionist's adherence to treatment protocol also emerged as a critical issue in our study. Because many of these Chinese PLWHA had no previous experience with psychological treatment, this study was the first opportunity they had to be “listened to” and to discuss in-depth their suffering and pain related to adherence and other matters, personal and social. As a consequence, it was easy for the therapy sessions to lose their focus. As evidenced in the nurse's progress notes, most of the participants spent more than one third of their sessions discussing how their relationships had been transformed by their HIV infection, and the fear and anxiety that had been generated by the overwhelming uncertainty of being HIV positive. In the future, mechanisms aimed at monitoring treatment adherence should be developed to ensure that all the topics are given full, in-depth coverage during the counseling sessions. However, at the same time, these outcomes indicate that there are tremendous unmet psychological needs among Chinese PLWHA, and medical adherence is only one of many concerns regarding their illness experiences. Given that HIV is still a

highly stigmatized disease in China, it should be remembered that decision on disclosure can alter social relationships drastically. In the future, researchers should consider relational and emotional factors when designing studies, and should explore how Chinese PLWHA's decisions on disclosure are likely to impact their adherence to treatment regimens. We also believe that inclusion of these relational and emotional factors may further improve the efficiency of the original intervention module.

Conclusion

Incorporating interventions like this one, in other words, interventions that successfully draw upon patient strengths and facilitating factors while overcoming culturally specific barriers to adherence, may be particularly helpful. Where resources are limited and patients are culturally diverse, it is imperative for practitioners to give greater attention to key cultural factors that may have interfered with or promoted PLWHAs' medical adherence. This evidence-based intervention provides a case example of the process of adapting behavioral interventions in which the local cultural and societal contexts are considered and integrated into the intervention through careful theoretical mapping.

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Table 1

Adaptation Process

		<u>Adaptation</u>	
Intervention Elements		Reasons for Adaptation	Response Strategies
	Content	Cultural assumptions: <ul style="list-style-type: none"> • Familial-collectivist culture • Interpersonal harmony • Reverence for authority • Yin-yang perspective on health 	<ul style="list-style-type: none"> • Building local adherence model • Adjusting and mapping interventions to the theoretical model • Feasibility check with local health-care providers
	Procedure	Cultural factors: <ul style="list-style-type: none"> • Respect for hierarchical power structure • Pragmatism • Confucian work ethic Societal factors: <ul style="list-style-type: none"> • Mental health-care providers are not widely available • Recruitment and payroll policies in the Chinese public health-care organization 	<ul style="list-style-type: none"> • Choosing CBT interventions <ul style="list-style-type: none"> – CBT can effectively respond to cultural factors – CBT has been documented to be efficacious in reducing Chinese PLWHA’s distress • Recruiting nurses within the organization as interventionists • Developing training protocols • Providing training and supervision

Table 2

Comparison Between Enhanced Intervention Arm and Regular Care Arm

	Completed	Dropped Out	Total
Enhanced Intervention Arm	36	0	36
Regular Care Arm	28	6	34
Total	64	6	70

Table 3

Comparison Between Original and Chinese Life-Steps Program

Culturally Adapted Chinese Life-Steps Program	Safren et al.'s (1999) Original Life-Steps Program
<ul style="list-style-type: none"> • Motivation and engagement • Interactive psychoeducation <ul style="list-style-type: none"> – Balance views of ART within Chinese cultural framework • Getting to appointment • Coping with side effects <ul style="list-style-type: none"> – Reconceptualize side effects as evidence of effectiveness <i>and</i> solve the conflicts between cultural beliefs and adherence • Communication with health-care providers <ul style="list-style-type: none"> – View health-care providers as working partners, rather than formal authority figures <i>and</i> maintain harmonious relationships with healthcare providers • Introduction of patients' HAART regimens • Medication scheduling, sorting, and storing • Reminder strategies • Handling slips • Problem-solving for additional barriers to adherence • Review • Utilization of treatment partners 	<ul style="list-style-type: none"> • Psychoeducation and introduction <ul style="list-style-type: none"> – Foster the perspective that the ART regimens are “health-protecting tools” • Getting to appointment • Coping with side effects <ul style="list-style-type: none"> – Reinterpret side effects as evidence of effectiveness • Communication with treatment team <ul style="list-style-type: none"> – Increase confidence in ability to discuss with treatment team • Obtaining medications • Concrete daily medication schedule • Storing of medications • Cue-control strategies • Guided imagery • Handling slips • Review