

## Obstacles to Conducting a Life Story Project with Chinese American Family Caregivers

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Rec date: Dec 19, 2016; Acc date: Jan 02, 2017; Pub date: Jan 04, 2017

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### Commentary

This short report is to document the obstacles to conducting an evidence-based life story project with Chinese American family caregivers, and to discuss modifications needed for increasing participation.

The call to develop program interventions that will address the cultural aspect of providing services to Chinese American family caregivers, enabling programs to improve caregiver well-being and sustain care to their loved ones, has been longstanding [1-3]. The life narrative, a therapeutic tool which uses reminiscence to provide discovery of deeper meaning and purpose in an individual's life [4,5], is a culturally competent technique widely used in social work and counseling. It helps caregivers to identify "purpose in life" as a psychological resource to help caregivers' sustain provision of care, and plays an important part in reducing the likelihood of caregivers' depressive symptoms [6]. Echoing the previous study, a study with professionals who had worked with Chinese American family caregivers revealed that to strengthen family caregiving services, professionals need to enhance their supportive roles by providing opportunity for Chinese American family caregivers to divulge their inner feelings and hardships [7].

To help Chinese American family caregivers view their lives in ways that are positive and constructive rather than as negative and dominated by problems and shortcomings, the life story project called "every caregiver has a story to tell" was implemented in a family caregiver program beginning 2016. Through the process of constructing and sharing life stories, stress due to caregiving can be reduced. A quasi-experimental pre-post research design was used to examine the effectiveness of a life story project on reducing caregiver stress. The investigator planned to meet with each family caregiver once a week for 3 weeks, with each session running for 45 minutes to an hour. Considering that some family caregivers were working, had other obligations, or for whom it was not feasible to come to the center, the investigator provided phone interviews at their preference. Semi-structured questions were developed based on the stress theory that served as a guideline to facilitate recall of their caregiving experience including the following: health status of the care receiver as well as the relationship to the family caregiver, the length and types of caregiver assistance provided, additional caregiving resources, caregiver's health status, and detailed assessment of caregiver stress and burden.

During the implementation of the project, the investigator experienced difficulty recruiting caregivers. The investigator was able to recruit 6 participants at the special meeting, but only one was willing to participate for follow-up. The reaction and willingness to participate in the project was below expectation. The investigator reviewed reasons for low response with several obstacles emerging:

there was only a one-time presentation of the life story project offered to attract potential participants, the investigator was not always available on site thereby limiting access to the project by family caregivers, many Chinese-American family caregivers have a culture of coming only when there is a caregiving crisis for which they primarily value an external and quick resolution. Marketing/referral of the project was also very limited due to posted flyers of the project at only one location and referral from the staff at only one program. Promoting and recruiting participants for the life story project is not a current priority of the clients, and therefore the staff, given current type of services sought by clients and the lack of resources and personnel for program expansion toward more internal change in clients. The caregiver program staffs' primary job capacity is to provide direct, practical services to daily assist caregivers (walk-in, crisis and appointment), which is a heavy workload already beyond their scheduled work hours, given their program success in reaching many citywide caregivers that are initially attracted to pragmatic external supports. All these factors led to low life story project perceived value, availability and participation rate.

A key issue in addressing past implementation issues is to first re-address that the life story project has been proven to have enormous internal support value and effectiveness of reducing stress that is not yet valued by the target population. Based on the above findings, the investigator has made the following changes to future implementation of the project including: effectively addressing the cultural understanding of internal coping skills, expanding research sites, increasing numbers of assistants/volunteers to promote the project and increased marketing venues. The investigator plans to expand research sites include senior centers and senior housing to recruit potential participants. Special meetings introducing and addressing practical gain of the project, will be set up to recruit interested individuals after the presentation. In addition, the investigator plans to seek funding to support research assistants for the research project. Student research assistants will be trained to conduct a life story session and reach out to potential participants by promoting the project regularly on site along with the investigator. In addition to increased numbers of assistants, the investigator plans to involve staff at the sites to actively promote the life story project. Staff will be encouraged to participate in the life story project so that they will have firsthand experience and better understand the value of the program. Through a trusting relationship of staff and clients, clients might feel the life story project more feasible and valuable.

With the above modifications, it is hoped that the life story project will be an effective part of the program and generate sufficient number of participants for research to examine the feasibility and effectiveness of the intervention on reducing Chinese American family caregivers stress [7].

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