

12-2017

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Sharing the Burden

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December 2017

Abstract

Family caregivers of hospice patients experience an increased burden due to providing ongoing care. Research on the issue produces no consensus on evidence-based programs to alleviate the burden. Respite or relief services continue to be the primary solution applied to the problem. Central Coast Visiting Nurse Association and Hospice supported a project to address caregiver burden. Hospice provides volunteers to families to reduce the caregiver burden. The project consists of outreach and recruitment to obtain new volunteers that continue to deliver respite within the community. Project duration lasted for approximately three months and was implemented by completing six tabling activities at public locations. Agency college interns participated and engaged in dialogue with community members. The intended goal was to recruit more volunteers before the cessation of the project. Recruitment was unsuccessful for the duration of the project however relationships with organizations developed where tabling occurred. Recommendations were made to the agency to continue the outreach and recruitment project because it had potential for obtaining volunteers over a longer implementation period. Additionally, the project activities did not increase expenses for the agency.

Keywords: *caregiver burden, hospice, respite, volunteers, outreach, recruitment*

Agency, Mission and Purpose

The Central Coast Visiting Nurse Association and Hospice (VNA) is a non-profit 501(c)3 community organization. VNA has provided home health care and hospice services for California residents of Monterey and San Benito Counties since 1951. Additionally, VNA serves limited areas of both Santa Clara and Santa Cruz Counties. Offices are located in the cities of Salinas, Hollister, King City, and a Monterey. Combined the agency makes more than 75,000 home visits each year. VNA and Hospice's mission is striving to provide quality healthcare for patients and develop individual plans to fit their needs. In continuing its mission, the VNA understands the guidelines in managing an effective nonprofit agency. The responsibilities include good fiscal management, caring about individuals, and conduct of a high ethical standard. VNA's vision involves continuing the role of a comprehensive regional home health agency and hospice provider while remaining not-for-profit. In addition, the vision is about achieving quality care through collaboration, innovation, and accountability. In creating a positive environment VNA will recruit and retain quality staff members. This achievement will grow the reputation of the agency as a brand of quality healthcare. VNA is licensed by the California Department of Health Services, Medicare and Medi-Cal Certified, HIPAA compliant (VNA & Hospice 2017).

Communities Served

VNA and Hospice serves age groups 18 years of age and older who have a medical prognosis with no more than six months to live, residing within the mission geographic area, regardless of socioeconomic status. Hospice patients tend to be generally elderly. In the year 2013, U.S., hospice patients in the 85 plus years' age category represented 41.2% of the total hospice population. Age 75-84 years made up 26. %, followed by ages 65-74 accounting for

16.6%. In comparison the age group representing 35 years or younger accounted for 4% of the total hospice population (National Hospice and Palliative Care Organization, 2014). Monterey County represents a significant portion of patients serviced by VNA and Hospice however research was unable to produce comparison information from the two other hospice agencies.

Information obtained from the 2010 United States Census on Monterey County, California indicated adults age 65 and over represented 10.7% of the total population. Male adults 65 and over were at 4.7% compared to 6% of females. (United States Census Bureau, 2017)

Problem Statement

In Monterey, San Benito, and Santa Cruz Counties, family caregivers of hospice patients experience increased burden providing ongoing care. Caregiver burden is defined as "the psychosocial and physical reaction to the imbalance of demands placed on the caregiver by various factors, including personal time, multiple roles, physical and emotional stress, financial resources, and formal care resources" (Bialon & Coke, 2012). Hospice care is intended to support the family caregiver and patient although limited options exist to help caregivers with their daily responsibilities of patient care. Caregivers of hospice patients face the simultaneous challenges of providing care for loved ones and coping with the anticipated death. One may imagine observing the slow or rapid decline of a spouse or parent and also ensuring to their daily well-being. In addition, their responsibilities may include management of the household duties, personal finances, and communicating with medical professionals. The situation often comes with new responsibilities and unfamiliar tasks that most never receive education, training, or paid compensation. Previous studies demonstrate the emotional and physical experiences involved with providing care can strain even the able caregiver. Family members, friends, and neighbors

are generally relied upon to share the burden. They are referred to as informal caregivers and account to contributing 43 to 97 hours per week to the care of individuals at the end of life. (Empeno, Raming, Irwin, Nelesen, & Lloyd, 2011). The impact upon the caregiver may last several months to years following the death of a love one. Family caregivers are on average, female (78.9%), spouses (41.5%), or children (39%) of the hospice patient (Albright, Washington, Parker-Oliver, Lewis, & Kruse, 2016). It is important to note in this report the National Hospice and Palliative Care Organization reports annually on demographics of hospice patients; however, national data and demographics are not readily available for hospice caregivers (Albright, Oliver, & Demiris, 2015). Hospice patient care is generally provided in the place the patient calls "home". In the year 2013, 66.6% of patients received care in the home. Nursing homes, residential facilities, and hospice inpatient facilities account for other places where patient care is provided (National Hospice and Palliative Care Organization, 2014). As more of the United States (US) population consists of aging adults, individuals begin to find themselves with a daunting task of caring for terminally ill family members.

Problem Model

<p><u>CAUSES/CONTRIBUTES TO:</u> Physical activities and emotional stress Demands of constant care Limited financial resources</p>	<p><u>PROBLEM</u> Family caregivers of hospice patients experience increased burden providing ongoing care</p>	<p><u>CONSEQUENCES</u> Depression Anxiety Reduced quality of patient care</p>
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Physical activities and emotional stress

There may be various factors contributing to the burden of caregiving upon families. One primary factor is the physical activities and emotional stress associated with caring for loved ones. Often, there is the requirement of moving and lifting patients from beds and wheelchairs. The day-to-day repetitive physical actions to assist loved ones to the restroom exhaust caregivers both physically and mentally. Some other tasks may include giving medications, pills, or injections. Grocery shopping, housework, and preparing meals are among the physical challenges of providing care. At times caregivers may perform typically nursing duties such as tube feedings, catheter, and other complex responsibilities. Caring for an individual with conditions such as Alzheimer's or cancer can increase emotional stress. The caregiver may become frustrated because the disease causes changes which make it difficult for communication. Patients may have substantial memory loss and the caregiver must develop new skills in response to the specific health condition (National Alliance for Caregiving, 2015).

Demands of constant care

Caregivers often feel the demands of constant care. A spouse or child of a hospice patient may often have obligations of part-time to full time employment along with round-the-clock care. Often accompanying the demand is the feeling the caregiver has of isolation from the world. They may have concern about leaving the home which makes it difficult to get exercise, connect with friends, or run errands. Commonly coexisting with caregiver isolation is their need of time alone away from caring for a patient. The actual responsibilities for the caregiver may be less constant; however, they feel they should always be available. Heavy burdens are placed on them as they live with the feeling of "always being on duty" (Scott, 2016).

Finances and employment

Financial issues contribute to the burden of caregivers as they navigate through personal and public resources to fulfill household expenses. Family caregivers may have to take considerable time off from careers or need to make changes to their work schedule to accommodate caregiving. The issue of leaving employment leads to reduced income for the household therefore, causing stress upon caregivers who lack financial resources (National Alliance for Caregiving, 2015). In most cases hospice services are most likely fully covered under government programs like Medicare or private insurance. The services include medical efforts to manage pain and ensure the comfort of the patient; however, families must still be expected to meet basic needs to pay for rents, mortgages, food, clothing, and utility services. The overall financial burden varies depending on the overall socio-economic status of the caregiver. Some families may have multiple savings or investments while others caring for a loved one lives pay- check to pay-check.

Consequences

Depression or Anxiety

The potential impact from the burden of caregiving may surface in various outcomes. One main concern is to consider the mental health effect on the family caregiver. The length of stress over a considerable period of time poses increase risk for developing either depression or anxiety. Older adults may be even more vulnerable due to age. Chentsova-Dutton et. al (2002) reports that "hospice caregivers experience higher levels of depression, anxiety, anger, and health problems than demographically matched, non-caring controls" (pg.54).

Reduced quality of patient care

Secondly, there is the consequence of the quality of the patient care because of stress associated with the caregiver. Once a caregiver is experiencing their own health problems, there may be the unfortunate result of not being able to properly care for patients. For example, a caregiver suffering from a mental condition may be unable to focus when assisting with a limited mobility patient; therefore, resulting in physical injury to the patient. The fact that caregiving requires continually balancing personal interests and managing patient medication, any mental disorder resulting from stress would negatively impact patient care. High caregiver burden and depressive symptoms are related to patients' quality of life (Hooley, Butler, & Howlett, 2005).

Project Description and Justification

The project that will address the issue of the burden upon family caregivers is called "Hospice Caregiver Volunteer Recruitment Program". Visiting Nurse Association & Hospice (VNA) currently has approximately 40 active volunteers engaged in various agency needs. The program is an outreach event and the goal of the program is to increase 2-3 volunteers from the period of September thru October 2017. Success of the program will be evaluated from data involving the number of volunteers recruited and satisfaction of relief services provided to family caregivers. Expansion of the number of volunteers could help to ensure the improved quality of agency services. Hospice volunteers support patients and their families through services to include companionship, vigil, and respite care. Family caregivers with limited resources often make respite care requests in order to obtain personal time, attend appointments, run errands, and sleep. Consequently, the agency's volunteer coordinator expresses the challenge to fulfill all respite requests for reasons to include volunteer availability, number of hours

requested, and short-term notice provided to the agency (E. Birruete, personal communication, 2017). An increase in volunteers would benefit the agency by increasing probability of ensuring all respite requests. The desired intermediate outcome would be to alleviate a significant portion of family caregiver burden.

The program would involve using current California State University, Monterey Bay (CSUMB) student interns assigned to VNA since they routinely perform the duties of a hospice volunteer. The majority of VNA interns from CSUMB study in the major of Collaborative Health and Human Services (CHHS) and have developed the knowledge, skills, and abilities to support the project. A question immediately posed is "Will CHHS interns consent to participation in the project"? The need for verbal or written consent will be required before the interns perform any of the outreach activities. The author of this report most likely can alone implement the activities of the program, however, collaboration to any endeavor is appreciated and ensures an improved outcome. The outreach activities would consist of tabling and presentation events at local colleges, public libraries, and civic engagement organizations. Student interns would educate and promote the hospice volunteer program at the outreach events through dialogue, brochure distribution, and perhaps brief presentations. The hope is to recruit service minded individuals who are looking to contribute portions of their free time. VNA would learn about effective outreach if recruitment efforts are successful through data collection and analysis. Data collection methods would involve (2) surveys. The first survey is provided during the volunteer's standard hiring orientation. The survey would involve questions to determine if the new volunteer heard about the agency due to one of the proposed outreach events. Additionally, volunteers who perform respite duty will ask caregivers to complete a Leichardt style scale survey to determine if the respite service alleviated some caregiver burden.

The survey would rate the service from very dissatisfied to very satisfied. The construction of the appropriate questions to ask in the surveys are currently a work-in-progress. Evaluation of the success of the project would follow data collection and analysis. Research has been unsuccessful at identifying an evidence-based project that could be used as a model for project development. VNA & Hospice does pursue recruiting because organizations that receive hospice Medicare benefits are federally mandated to deliver five percent of patient care services from trained volunteers (National Hospice and Palliative Care Organization, 2016). The proposed project is intended to build on and support the current agency model of using volunteers to provide patient services.

Project implementation plan

Implementation of the project will begin in late August 2017 and expected to end in late October 2017. The first phase of the project will involve producing a list of local institutions and organizations that may authorize VNA to setup a table display intended for volunteer recruitment. Contact will be made via phone, email, or in- person with the listed organizations to request authorization. Upon receiving authorizations or declines, a master list will be finalized for further planning. The next step would be to schedule the dates and times of the tabling events at the selected organizations and institutions. Once the event scheduled is developed, it will be reviewed by the agency volunteer coordinator for approval. The second phase of the project will focus on the development of literature, surveys, and consent forms. Numerous amounts of agency recruiting brochures may be used or current ones can be developed from older models. Two (2) surveys will be created for both new volunteers and hospice family caregivers. A program spreadsheet would be used to input data received from the surveys. The final step in this phase would be to create consent forms from current volunteers/interns to participate in the

project. The third phase of the project involves assigning participating personnel to the listed scheduled tabling events. Tabling events will be schedule in two (2) hour increments and participants will be provided the resources (i.e., promotional materials, agency tablecloth) necessary to promote the VNA volunteer recruitment. Recruited volunteers will be referred to the volunteer coordinator for new hire processing. New volunteers are then provided with a survey asking the question "How did they hear about the VNA & Hospice volunteers along with biographic information requests. Coinciding with the tabling events, volunteers who are assigned respite care will be provided the satisfaction surveys. Volunteers will ask the family caregiver to complete the surveys and then return them to the project manager. The final phase of the project involves data analysis and program evaluation.

Assessment of the Project Outcome(s)

An expected outcome of the CCVNA outreach and recruitment project was to increase the number of volunteers within the organization. A modest objective was to complete recruitment of 2-3 individuals following the completion of all tabling activities. All newly hired volunteers must complete required documentation, health screen, and criminal background check. Failure in meeting any of the requirements may disqualify a candidate from working as a volunteer. In addition, any recruited individual must have been the direct result of the project's tabling activity.

A second outcome of the project would be to ensure all requested respites by having more volunteers. Family members are able to temporarily receive respite for several days and have their patient transferred into a skilled nursing facility. Many family caregivers elect instead to use the volunteer option to obtain respite. Hospice staff routinely advise caregivers to plan

accordingly and provide advance notice when making a request for service. The CCVNA Hospice Volunteer Coordinator must face the daily challenge of balancing between volunteer availability and granting the service at the specified date/time for the caregiver. Increasing the agency volunteer pool may increase probability of meeting short notice urgent requests from the caregiver.

A third outcome would be to bring awareness of family caregiver burden to members of the local community. Outreach events provide the opportunity to educate the public about the services of hospice and the important role of the family caregiver. The event facilitator is able to engage in dialogue with individuals who develop interest in the area of hospice patient caregiving. Consequently, persons may pursue an effort at a later date to become a volunteer.

The final outcome would be to determine if the family caregivers within the CCVNA service area perceive they are experiencing an increased burden. Caregivers may then report burden to an agency medical social worker or clinical manager and receive supportive services. The unavailability of any publication, report, or assessment presents challenges to know the severity of the problem. A sampling survey of the family caregiver population may provide insight of the larger group and validate the prevalence of burden.

One of the measures used to assess the effectiveness of the outreach and recruitment was the employee orientation process. Upon hire every new volunteer completes the required employment documents which are then submitted to the agency human resources department. Included within the forms is a questionnaire administered by the volunteer coordinator to determine what form of advertisement brought the individual to the agency. The provided options on the form include newspaper ad, online ad, personal referrals, and tabling event. The

volunteer coordinator would then report any recruitment as a direct result from the six outreach and recruitment events.

A second measure to assess respite service delivery is the direct reporting of the volunteer coordinator. On a weekly basis the coordinator reports on the success/failure of providing all respite service requests from family caregivers.

The third measure on bringing awareness to the issue of caregiver burden was to engage in dialogue with a minimum of four community members during each tabling event. Facilitators would discuss and provide information about the purpose of hospice and the importance of how volunteers serve the patient and their families. Each contact with a community member was tracked on a clipboard log. Individuals which expressed an interest of becoming a hospice volunteer were asked for contact information. The names acquired were provided to the agency coordinator for a follow-up call/email.

Five tabling activities were completed as a measurement of outcome. One of the activities were implemented during community events in the City of Monterey. Four of activities occurred within public libraries in the both the cities of Salinas and Marina.

Final assessment measure on the prevalence of family caregiver burden would be completed by administering a minimum of seven surveys (see appendix B) to caregivers following a respite service by an agency volunteer. Caregivers were given the option of filling out the surveys themselves or having the volunteer assist with writing in the responses. A total of eight questions were asked on the issue.

Project Results/Findings

The scope and duration of the project initiated a challenge in securing logistics, communication, collaboration, and planning. In the original timeline making contact with all the proposed organizations should have been completed within 2-3 days near the end of August 2017. The actual phone calls or emails sent to individuals, who had authority to approve tabling occurred within 1-2 weeks of each of the six tabling activities.

One of the first requests for a tabling activity was to a regional hospital. Contact information was obtained through the hospital website and an email was sent requesting permission for the tabling event. Within two days a representative from the hospital responded and said the request would go under review. The result arrived in an email declining the request based upon limited space. A second denied request to a non-profit agency serving aging adults revealed the difficulty obtaining cooperation. Upon consultation with VNA's volunteer coordinator it was decided to seek authorization from public libraries or civic organizations.

In the first activity located at the Monterey County Fairgrounds VNA participated in a consortium with approximately 15 other agencies. Community members wandered among the tables and were more interested in gathering free promotional items on each table than obtaining information. One important overlooked project item was a tracking form to collect contact information from interested parties. Individuals who expressed interest were provided with the agency phone number and advised to contact the volunteer coordinator.

Public libraries in the cities of Salinas and Marina provided a high degree of support and courtesy for the project. The head librarians replied to emails within a few days and expressed enthusiasm for the research. Tables were reserved for use in Salinas while Marina library made available a community meeting room. Pacific Grove's Carnegie Library was a site identified

because respite requests were initiated by residents of the city. Attempts made via phone/email to contact a head administrator for approval were unsuccessful.

Recruitment of 2-3 volunteers through the outreach activities was not achieved. VNA volunteer coordinator did not report obtaining volunteers due to the project. Two specific young woman in the 20-30 year old age range stated they would appear at an orientation event however, failed to attend. The events may have not been scheduled appropriately to attract older adults who are service oriented and likely to volunteer for charitable organizations.

The project did achieve outreach and promoted awareness to approximately 15 members of the community. Members may later arrive at a decision to become a VNA volunteer. Secondly, agency college intern participants were able to obtain experience and improve their skills in public communication.

Strengths of the project design are in the framework of locations that can be used during future dates to promote the mission of the agency. Additional strengths include no increased expenses to the agency in continuing project activities.

Results of a survey (see appendix b) provided by agency volunteers to family caregivers following completion of respite service. Participants were randomly selected and asked if they experienced some degree of burden in providing care and if the respite service provided some relief:

n=7

Participants self-report experiencing some degree of burden 86%

Participants self-report respite service provided some relief 100%

Personal reflection

Conclusions/Interpretations

The outreach and recruitment for hospice volunteers was unsuccessful with an immediate outcome of obtaining 2-3 new individuals within the three-month duration. Six outreach activities were successfully implemented and contacts were produced with administrators at four public libraries within Monterey County. A small network of institutions was established and may be used to increase community outreach. Recommendations to the agency would be to continue the project as it has the potential to increase volunteer recruitment. Secondly, continuing college interns have developed the experience and skills necessary to perform outreach without increased agency costs. Materials (i.e., brochures, promotional items) currently used in agency fundraising activities can additionally be used for recruitment activities. Current agency interns can train future interns and ensure the sustainability of the project. Over the course of time the volunteer coordinator may refine the process and collaborate with civic organizations to grow a larger recruitment network. Increasing the volunteer base is vital to providing respite services which contribute to reduce family caregiver burden.

Professional Growth

The issue of family caregiver burden was inspired following a completion of respite care. A woman was experiencing the challenge of providing 24-hour care for her husband of nearly forty years. She was the primary caregiver and discussed the difficulty in completing everyday assisted living tasks. Knowledge obtained about the problem is that "caregiver burden" has been extensively researched using qualitative methods. Research on this project is unable to reveal

quantitative research on the severity of the problem. Peer reviewed articles provided no data on the number of family caregivers experiencing the problem at the local, state, or national level within the United States. Secondly, in order to begin to address issues related to health and human services, there must be a thorough understanding of the problem. Planning and implementation involve developing a list of activities and securing resources that may be limited. It requires collaboration both inside the agency and with agency partners. This project contributed to VNA because it complemented on the recruiting efforts to secure volunteers that provide respite care. Respite is the primary tool used to help reduce family caregiver burden.

Broader social significance

A broader health or social problem related to this project is the issue with aging. As more of the population ages more families become burdened with caring for their loved ones extensively. Problems associated with aging such as Alzheimer's disease increase the demands for assisting family caregivers. This project helps to identify the importance on how volunteers contribute to the quality of life for aging patients.

Steps that should be taken to address the issues related to aging is being able to identify early families which may have limited resources in providing care. Education should be readily available to provide families options so they use services to prevent health related problems for themselves.

Advice that is beneficial for future capstone students is to remain flexible on time spent at the VNA. Opportunities to learn will arrive during various experiences and contact with patients, nurses, medical social workers, and administrative staff. Interns would be advised to look at reinforcing existing agency programs.

References

- Albright, D., Washington, K., Parker-Oliver, D., Lewis, A., & Kruse, R. (2016). The social convoy for family caregivers over the course of hospice. *Journal of Pain and Symptom Management*, 2(51), 213-219.
- Bialon, L., & Coke, S. (2012). A study on caregiver burden. *American Journal of Hospice and Palliative Medicine*, 3(29), 210-218.
- Empeno, J., Raming, N., Irwin, S., Nelesen, R., & Lloyd, L. (2011). The hospice caregiver support project: Providing support to reduce caregiver stress. *Journal of Palliative Medicine*, 5(14), 593.
- Hooley, P., Butler, G., & Howlett, J. G. (2005). The relationship of quality of life, depression, and caregiver burden in outpatients with congestive heart failure. *Congestive Heart Failure*, 6(11), 303-310.
- National Alliance for Caregiving. (2015). *Caregiving in the U.S. 2015 - Executive Summary*. Retrieved May 3, 2017, from <http://www.caregiving.org/caregiving2015>
- National Hospice and Palliative Care Organization. (2014). *facts and figures: hospice care in america*. Retrieved March 9, 2017, from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf
- National Hospice and Palliative Care Organization. (2014). *NHPCO's Facts and Figures: Hospice Care in America*. Retrieved May 2, 2017, from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf
- National Hospice and Palliative Care Organization. (2016). *National Volunteer Week*. Retrieved May 10, 2017, from <https://www.nhpco.org/press-room/press-releases/national-volunteer-week-2>
- Scott, E. (2016). *Common causes of caregiver stress*. Retrieved May 3, 2017, from Verywell: <https://www.verywell.com/common-causes-of-caregiver-stress-3144519>
- United States Census Bureau. (2017). *american fact finder*. Retrieved March 8, 2017, from <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>

Visiting Nurse Association and Hospice. (2017). *About VNA*. Retrieved March 8, 2017, from <http://www.ccvna.com/about-vna.htm>

Appendix A

Activities	Deliverables	Completion
Develop contact list	Excel sheet to contact libraries for tabling	8/27/17
Table Monterey County Fair	1 contact	9/1/17
Gather agency literature	Distribution items for tabling	9/13/17
Table Caesar Chavez library	2 contacts	9/20/17
Table Caesar Chavez library	1 contact	9/26/17
Table Steinbeck library	0 contact	9/27/17
Table Marina library	0 contact	10/24/17
Create & distribute family caregiver survey	Survey to receive data on family caregiver burden	10/24/17
Evaluate events & surveys	survey responses	11/1/17

APPENDIX B

Family Caregiver Burden Survey

The following voluntary survey is used to support a student academic project at California State University Monterey Bay. The intent is to gather information about the impact of respite services used by family caregivers of hospice patients. Responses to the survey are confidential and any information provided cannot be used to identify a participant.

1) What is your relationship to the patient?

- spouse
- son
- daughter
- Parent
- relative/extended family (i.e., cousin, aunt, uncle, grandchild)
- other _____

2) Do you provide daily care to the patient?

- yes
- no

3) How long have you been providing care since the patient was admitted to hospice?

- <1 month
- 1-3 months
- 3-6 months
- more than 6 months

4) Do you experience some degree of burden providing ongoing care to the patient? (i.e. stress, employment schedule, lack of personal time, unfamiliarity with new duties)

- yes
- no

5) Did this respite service today provide some relief?

- yes
- no

6) What is your gender?

- male
- female
- transgender
- other _____

7) Please indicate your age category.

- 18—24
- 25—34
- 35—44
- 45—54
- 55 >

8) Which of the following best represents your racial or ethnic heritage? Choose all that apply.

- White/Caucasian
- Black/ African American
- Asian/Pacific Islander
- American Indian or Alaskan Native
- Hispanic/Latino
- Multiple Ethnicity/Other (Please specify) _____

Thank you for completing the survey!