

Behavioral Health Aides in Rural Alaska: Their Experience in Caring for Alaska Native Cancer Survivors

Stacy F. Kelley · Christine DeCourtney · Xiomara Owens

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Abstract The Alaska Native Tribal Health Consortium conducted a statewide survey of rural community behavioral health aides (BHAs) within the tribal health system to assess their need for psychological and emotional support training for their work with cancer survivors. An electronic survey was distributed to all 114 rural BHAs in Alaska. They were asked about cancer survivors living in their community, whether they had been called to provide counseling to those survivors and about their comfort level in addressing cancer-related emotional issues and concerns experience by the patients and their families. Sixty-one (54 %) BHAs responded, 62 % knew of cancer survivors in their community, and 88 % of whom agreed that it is their job to provide support to those cancer survivors. Of the 47 % of BHAs who had provided counseling to cancer survivors, 63 % noted a lack of adequate training about how to provide that counseling. Dealing with “emotional concerns” was reported as the most difficult issue. Almost all (98 %) reported that they would likely participate in training to improve counseling skills. Most BHAs in rural Alaska know of a cancer survivor in their community and may be called on to provide mental health services, but few report adequate training in how to provide these services. Given the remote locations in which many BHAs work and the lack of local resources to guide them, more education is needed about how to support cancer survivors. This study provides information to help guide development of content of that education.

S. F. Kelley · C. DeCourtney
Department of Clinical and Research Services, Alaska Native Tribal Health Consortium, Anchorage, AK, USA

X. Owens
Department of Behavioral Health, Alaska Native Tribal Health Consortium, Anchorage, AK, USA

S. F. Kelley (✉)
Alaska Native Tribal Health Consortium, 3900 Ambassador Drive
D-CHS Suite 401, Anchorage, AK 99508, USA
e-mail: sfkelly@anthc.org

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Introduction

Prior to the mid-1900s, cancer was considered a rare disease among Alaska Native people. Since that time, however, cancer incidence has increased substantially [1]. Cancer incidence rates are high among Alaska Native people and the rates of many types of cancer exceed that seen in the US white population [2].

Cancer Survivors in Rural Alaska

Currently, there is an estimated 30,000 people who have been diagnosed with cancer in Alaska [3]. With a state population of only 731,000 [4], this means that 4 % of the population (one of every 25 Alaskans) has been diagnosed with cancer. The term “cancer survivor” refers to those people who have been diagnosed with cancer and is sometimes used to also refer to the people in their lives who are affected by their diagnosis, such as family members, friends, and caregivers [5]. Survivorship begins from the time of diagnosis and continues through the remaining years of a patient’s life [6]. Cancer survivors may face numerous physical, psychological, social, spiritual, and financial challenges. Often times, the psychological issues associated with cancer diagnosis and treatments include fear, stress, depression, anger, and anxiety, along with feelings of helplessness, lack of self-control, changes to self-esteem and self-image for the survivor, and stress and anxiety for their caregivers [7].

Health Care Rural Alaska

Although the rate of cancer is particularly high in Alaska, other rural areas of the United States also report higher

prevalence of chronic diseases [8] that include cancer, a finding that has been attributed, in part, to a rural population that is older, poorer, and less educated [9]. In Alaska, vast distances, remoteness of rural communities and differences in language and culture influence the care and support of cancer survivors. Sixty percent of Alaska Native people live in small villages of 20–1,700 people scattered across 570,640 mile² [10]. Most of these villages are not accessible by road, and can be reached only by airplane or boat in the summer and by airplane or snow mobile in the winter [11].

Most cancer survivors living in rural Alaska communities receive their medical care from community health aides. Community health aides provide emergency, acute, chronic, and preventive health care for all ages. Community health aides are not unique to Alaska, however. Many rural health care systems throughout the world include lay health care workers (similar to Alaska's community health aides) who are community members who serve as natural helpers [12]. In other areas of the United States lay community health workers (CHWs) serve as “bridges” between community members and health care services [13, 14], although, they go under a variety of names such as community health advocates, lay health educators, community health representatives, peer health promoters, community health outreach workers, and “promotoras de salud”.

The Alaskan based Community Health Aide Program (CHAP) has well-defined procedures for selecting aides, providing education curricula, setting training standards, and establishing criteria for certification [15]. Community health aides are now the front-line providers in a comprehensive integrated Alaska Tribal Health System [16]. While these individuals receive extensive training about management of physical health issues, they receive little training about addressing the emotional and mental health needs of cancer survivors and their families.

Behavioral Health Aide Program

In 2005, the US Indian Health Service (IHS) formalized its intention to address the social and mental health issues of American Indian/Alaska Native (AI/AN) communities when it initiated the Behavioral Health Initiative [17]. As part of this initiative, the Alaska Native Tribal Health Consortium (ANTHC) based in Anchorage used CHAP as a model for training and deploying a new workforce of individuals, named “behavioral health aides” (BHAs).

A BHA is a village-based counselor, health educator, and advocate for whom training is focused on addressing community behavioral health needs. Most BHAs come from the community in which they live and are trusted by community members. This allows them to combine their sensitivity to cultural needs with their specialized training in behavioral health.

The BHA program is structured as a multi-level provider model, starting with BHA trainees (non-certified, training towards certification). The next level includes certified BHA I and BHA II, who provide routine contact, intake services, early intervention, and community engagement activities. The highest levels of certification are for BHA III and behavioral health practitioners, who complete assessments and treatment planning and provide general supervision of BHAs I and II. A network of 15 established BHA directors are responsible for the BHAs within the Alaska tribal healthcare system.

Despite the broad training provided to BHAs, the scope of their education generally focuses on mental health issues related to substance abuse, grief, depression, and suicide prevention. Education is more limited about the mental and emotional health issues related to chronic medical diseases such as cancer. The existing cancer education courses for Alaskan based community health workers, including BHAs, focus more on modifying risk factors and encouraging individuals to undergo recommended screening exams, rather than dealing with patients who actually have cancer. Nationally, the LIVESTONG Foundation developed the Cancer Survivorship Training Curriculum for Promotoras. The training is one of the few cancer survivorship educational resources for lay community health workers that touch on the emotional concerns of cancer survivors.

Little is known about the extent to which BHAs are called upon to deal with the emotional and mental health needs of cancer survivors, or how they provide support to those with cancer within the constraints of a rural village setting in remote Alaska. Furthermore, a literature review did not identify publications regarding the extent BHAs and other lay health care providers interact with cancer survivors. We do know, however, that Alaska's BHAs have requested cancer information to supplement their basic training [18]. The objective of this study was to gather information to describe the experiences BHAs have in providing mental and emotional support of Alaska Native cancer survivors and their families in rural Alaska, and, thereby, generate recommendations for what might be the key focus of that additional education.

Methods

Study Participants and Survey Methods

In September 2012, an electronic survey was distributed by listserv to all 114 BHAs in rural Alaska using Survey Monkey [19]. A gift bag incentive was provided through a raffle for those who participated. The survey was sent three times to the listserv over a month-long period. The content of the survey instrument, survey procedures, and all other aspects of the study methods were reviewed and approved by the appropriate tribal agencies.

Survey Instrument

The survey was developed and pilot tested with several trainees and faculty of the BHA program. The final survey instrument contained 28 questions regarding (1) BHA experience caring for cancer survivors in their community, (2) community support, (3) cancer education, (4) cancer resources, and (5) BHA demographics.

BHA Experience Caring for Cancer Survivors in Their Community

BHAs were asked five questions about their current experience working with cancer survivors in their communities. The first question asked if the BHAs knew of anyone in their community who had been affected by a cancer diagnosis and its treatment (hereafter referred to as a “cancer survivor”). A second question asked if, when someone in their community has been diagnosed with cancer, most people in the community knew about it. The third question asked if they felt cancer survivors avoided talking with people in their community about their cancer experience and a fourth question asked if people in the community were afraid to talk to the cancer survivor about the cancer. The fifth question asked the BHAs to identify concerns they have when talking with a cancer survivor and gave a list of response options (from which multiple responses could be selected) that included not knowing: (a) what to say, (b) what to do, (c) how to address the survivor’s fears about reoccurrence, (d) how to help with cancer survivorship-related depression, anxiety, and uncertainty, (e) how to address physical concerns such as pain assessment and management, (f) how to talk to family members or caregivers, and (g) where and how to refer cancer survivors to survivorship resources.

Community Support

For those BHAs who knew of a community member who had completed cancer treatment and returned back to the community, a separate set of questions was asked. One question asked if the BHA had spoken with the individual who had cancer and with the individual’s family. A second asked if the BHA provided formal counseling support to the individual or family. A third question asked if they felt they had the proper training to provide support to the survivor. A fourth question asked them to select from a list of topics that were difficult to discuss, including physical concerns, emotional concerns, none, and other. They also were asked if anyone else in the community provided formal counseling support to the cancer survivor or the survivor’s family and to list which professionals were helpful, including visiting physicians, nurse practitioners/physician assistants, nurse,

community health aides, social workers, personal care attendants, clergy, and others.

Cancer Education

BHAs were questioned about whether they felt it was part of their job to provide support to cancer survivors, if they had received training to talk with cancer survivors and their families, and if they had received any specific cancer education training. They were also asked if emotional support for cancer survivors might be better addressed by someone else in their community.

Cancer Resources

BHAs were asked if they knew where to find cancer survivorship information and how likely it would be that they would take the time to learn more about how to support survivors and their families. From a list of choices, BHAs were asked what areas of cancer survivorship they were most interested in learning. The choices included (a) how to talk with a person diagnosed with cancer, (b) how to assist in finding support groups, (c) how to assist in finding support resources, (d) coping with changes in the family, (e) treatment side effects on a person’s sex life, (f) effects of cancer on partners, (g) adjusting to changes in body and self-image, and (h) dealing with fear/anxiety/depression for survivors/family/caregivers. An additional question asked BHAs how they prefer to access training opportunities (through webinar or teleconference training, in-person training at a meeting, internet resources, or print material). They were also asked two open-ended questions. The first was “what is your biggest concern working with cancer survivors in your community?” The second was “what else do you want to share about working with cancer survivors in your community?”

Demographics

In the last section, questions regarding BHA demographic characteristics were asked and included requests for information on age, gender, practice location, years in practice, level of training, and ethnicity. They were also asked if they were cancer survivors themselves or if cancer survivors in their community were related to them.

Findings

Of the 114 BHAs who received the survey, 61 completed and returned it for a 54 % response rate. The BHAs who responded were mostly female (86 %), over the age of 50 (56 %), and were of Alaska Native ethnicity (74 %). These demographic characteristics are similar to the demographics

of the overall population of BHAs. Respondents represented all five distinct areas serving the Alaska Native cultural subgroups: Inupiaq; Athabaskan; Yup'ik and Cup'ik; Aleut and Alutiiq; and the Eyak, Tlingit, Haida and Tsimshian. Over half of BHAs who responded (58 %) had only been a BHA for 2 years or less. Many (42 %) BHAs reported that they were related to a cancer survivor in their community. Several (12 %) reported being cancer survivors themselves. Four BHAs (7%), did not complete the demographic section of the survey. Table 1 summarizes these and other demographic characteristics of respondents.

BHA Experience with Cancer Survivors in the Community

Most (82 % of respondents) BHAs knew of a cancer survivor in their community, and 79 % reported that most people in the community knew this individual was a cancer survivor. Just over half of BHAs (57 %) reported that most cancer survivors avoid talking about cancer with others in the community, and 49 % reported that community members are afraid to discuss cancer with the survivor. Of the various concerns that BHAs have when talking with cancer survivors after treatment, the most commonly cited concern (noted by 57 % of respondents) was how to deal with survivorship-related depression, anxiety, and uncertainty (Table 2).

Community Support

Of respondents who knew of a community member who had completed cancer treatment and returned to the community, 77 % had spoken to the individual and the individual's family and 47 % had provided formal counseling support. Of the 47 BHAs who provided support to cancer survivors in their village, 63 % reported that they did not feel they had the proper training to provide this support. The most difficult topics to discuss, reported by 60 %, again were “emotional concerns” related to depression, anxiety and uncertainty.

Eighty-five percent of BHAs reported that other health care providers also provide support for cancer survivors in their village. Community health aides were mentioned most often (cited by 60 % of BHAs); others included visiting physicians (39 %), nurse practitioners and physician assistants (30 %), clergy (22 %), social workers (19 %), and nurses (16 %).

Cancer Education

Although 88 % of BHAs reported that it is part of their job to provide support to cancer survivors, 83 % stated that they did not feel they had enough training to do this and 81 % reported receiving no specific cancer survivorship education. In fact, about half (53 %) of BHAs said that providing support for cancer survivors might be better addressed by someone else.

Table 1 Respondent demographics

Demographics	No. (%) n=57 ^a
Gender	
Male	8 (14)
Female	49 (86)
BHA training level	
BHA trainee	15 (26)
BHA 1	9 (16)
BHA 2	6 (10)
BHA 3	13 (23)
BHA practitioner	14 (25)
Years in practice	
Less than 1 year	9 (16)
1–2 years	24 (42)
3–5 years	12 (21)
More than 5 years	12 (21)
Age	
21–29	4 (7)
30–39	8 (14)
40–49	13 (23)
50–59	16 (28)
60 and older	16 (28)
Race/ethnicity	
Alaska Native	42 (74)
American Indian	4 (7)
White/Caucasian	9 (16)
Other	6 (3)
Personally diagnosed with cancer?	
Yes	7 (12)
No	50 (88)
Know a community member who has completed cancer treatment	
Yes	50 (82)
No	11 (18)

^a 61 individuals responded to the survey, but only 57 provided demographic information

Table 2 Behavioral health aide's concerns about talking to cancer survivors after treatment

Behavioral health aide concerns	Number (%) n=61
How to deal with survivorship related depression, anxiety and uncertainty	34 (57)
What to say	32 (53)
How to deal with the survivor's fears about death	30 (50)
Where and how to refer clients for more resources	29 (48)
How to deal with physical concerns such as pain assessment and management	28 (47)
How to talk with family members and or caregivers	23 (38)
How to talk about fears about death	21 (35)
What to do	15 (25)

Cancer Resources

Currently, BHAs obtain survivorship information and resources through Internet searches, local and statewide tribal health organizations, and through their BHA supervisors/directors. Almost all (98 %) responding BHAs reported that they would be very or somewhat likely to take time to learn more about supporting cancer survivors and their families. The specific issues about which most BHAs had interest in learning are coping with changes in the family (79 %), dealing with fear/anxiety/depression for survivors/family/caregivers (76 %), how to talk with a person diagnosed with cancer (74 %) and adjusting to changes in body and self-image (72 %). They also had interest in learning about the effects of cancer on partners (62 %), and how to assist in finding support resources (52 %).

Most BHAs (88 %) identified in-person training at meetings as a preferred mode of training. Almost half (48 %) also favored webinar teleconference training.

In response to the open-ended questions about concerns working with cancer survivors and what they wanted to share about working with cancer survivors, the BHAs offered several comments. They expressed concern about not feeling part of the medical health care team. They also reported little or no communication and frustrating relations between themselves and village-based community health aide. One BHA commented, “I want to be part of the care team from the beginning to offer support for the client and the family.” Another BHA stated, “There is no team to tag onto. I am concerned with providing support all alone.” Others highlighted misunderstanding confidentiality practices between providers, with comments such as the following:

Rarely am I enlisted to assist with any cancer survivors. Generally the CHAP does home visit, etc. and health information is confidential so it is not discussed (with me).

BHAs indicated a desire for scripted language and suggestions on “what to say” to a cancer survivor, as well as how to react to the information being shared by survivors and their family members. BHAs commented, “I wish I knew how to talk to the survivor for emotional support and more information on how to deal with client’s emotions.” They also expressed how difficult the topic of cancer was to address. “To me, cancer is very hard to talk about. I would not know what to say, or even where to begin.” Additional BHA comments related to how their role as a BHA in small rural communities made the situation more difficult at times:

I wonder about outreach to cancer survivors/families, when is the right time to approach them, sometimes we hear the prognosis isn’t good and it makes it more

difficult to approach people. I find it much easier to approach someone on a personal level than a professional one.

Other concerns expressed by BHAs included how to talk about death, how to provide resources for survivors and their families, and how to provide realistic hope, dealing with confidentiality and addressing the stigma of cancer.

Discussion

The most important finding of our study is that although most BHAs in rural Alaska Native communities are called on to provide counseling and support for cancer survivors and their families, they have received little education on how to do this and they often feel ill prepared. Indeed, fewer than 20 % of BHAs responding to the survey felt that they have the training and skills to provide behavioral health support to cancer survivors. Just over half felt that supporting cancer survivors, their friends, family, and caregivers might be better addressed by someone else in their village despite their specialized training in behavioral health. The reluctance reported by BHAs is not surprising due to the lack of specialized training, feelings of not being part of the healthcare team, and may highlight AI/AN cultural beliefs that to talk with a patient with cancer is to invite evil spirits or death into one’s own body or family [20]. Trainings on difficult subjects such as cancer, death, and dying are often accessed on an as-needed basis. Similar to all cultures, unfamiliarity with the topic of cancer while working in an isolated environment may lead to the reluctance of specialized training. Outreach and dissemination efforts to promote the training should address cultural concerns and highlight the diversity and importance of services provided within their practice preview.

BHAs also reported a lack of awareness of about survivorship-related referral resources. In addition, they identified a gap in communication between BHAs and other healthcare providers. Users of mental health services often move between different primary and specialized health and care services, depending on their need for and response to treatment. This often leads to fragmentation of care. System changes that might avoid this fragmentation could include allowing BHA access to patients’ medical files and more longitudinal involvement of BHAs in patient care and mental health referrals.

Given the isolated rural Alaska Native communities in which many BHAs work, ranging in size from about 20 residents in the smallest villages to only several thousand in regional centers [21], BHAs need to have the skills to function effectively and independently. Our study results document a need for additional training and the BHAs responses to the survey provide information on the specific issues about which

training should focus. Furthermore, BHAs reported a willingness to participate in this training and recommended in-person training or webinars/teleconferences as the preferred modes of education.

Based on the survey results, the following training topics are recommended as the focus of curriculum development and training efforts: (a) introduction to cancer and the cancer care continuum, (b) what do I say to a cancer survivor, (c) addressing the emotional concerns of cancer survivors, (d) addressing the stigma of having cancer, and (e) working with the healthcare team in the village and with the resources available.

Several limitations should be noted when interpreting the study results. The most important is that although we distributed the survey to all BHAs working in Alaska Native communities, only 54 % responded. Thus, there is a possibility of response bias, with BHAs lacking interest in the topic of cancer survivorship being less apt to respond. We believe this bias is unlikely for two reasons. One is that distribution of this survey was the first time Alaska's BHAs have been contacted via listserv to solicit their opinions as a group, and it may merely have been lack of familiarity with the survey procedures that led to a less-than-complete response rate. In addition, the demographics of the responding BHAs were similar to the demographics of the overall BHA population.

A second limitation is that there is a high turnover rate among BHAs, so it is possible that if repeated on a different occasion, survey results might be somewhat different than the results reported here and might show BHAs to have more confidence in their ability to counsel cancer survivors. We feel that is unlikely, too, as a high turnover rate would lead to more "new" or "novice" BHAs who would be even less likely to have confidence in their skills at counseling cancer survivors than those with longer tenure.

Finally, this study was conducted in rural Alaska Native communities and the results may not be specifically generalizable to other behavioral health systems or other areas of the country. However, they still have relevance to health professionals working in any rural area and to the development of educational programs for such individuals.

Conclusions

Most BHAs in rural Alaska Native communities are called on to provide mental health services for cancer survivors, but few have had training in how to provide these services. Given the remote locations in which many BHAs work and the lack of local resources to guide them in their work, more education is needed about how to work with cancer survivors. This study provides information to help guide development of content of that education and has been valuable in developing the cancer survivorship training curriculum for BHAs. Many of the concerns expressed by BHAs are common in a variety of geographical and ethnic settings outside of Alaska. The

assessment tool used in this study can be modified to reflect these differences and used in other populations.

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