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STORY: THE HEARTBEAT OF LEARNING CANCER EDUCATION FOR ALASKA NATIVE COMMUNITY HEALTHCARE PROVIDERS

Abstract

Community Health Aides and Community Health Practitioners (CHA/Ps), the primary providers of healthcare in rural Alaska, share the importance of story as a culturally respectful way for creating meaning and broadening understanding. Story is woven into the fabric of cancer education courses for CHA/Ps. Between May 2004 and April 2007, 13 week-long cancer education courses were provided for CHA/Ps. In response to the written, end-of-course, evaluation question, ‘Do stories help you to learn? If yes, how?’ Ninety-six percent (96%) of respondents (99/103) described ways that story supported their learning. Additionally, in May 2005, 293 (65%) of the 454 CHA/Ps responded in writing to a mailed cancer education survey. Of the survey respondents, 240 (86%) were women and 239 (86%) were Alaska Native people. Nearly all, 98% (224/229) of Alaska Native people and 93% (37/40) of non-Native people identified story as helping them learn. CHA/Ps, on both the cancer education course evaluations and the CHA/P written survey, identified story as a pathway for connecting people, facilitating understanding, enhancing remembering, engendering creativity, expanding perspective, envisioning the

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future and inspiring possibility. Through stories we share our feelings, heal wounds, deepen understanding, strengthen community and discover hope.

Keywords: adult education, storytelling, Indigenous learning, cancer education

Introduction

Storytelling is at the heart of being human. Through stories we share our feelings, heal wounds, deepen understanding, strengthen community, and discover hope. Loretta Outwater Cox, an Alaska Native woman and author of The Storyteller's Club: The Picture-Writing Women of the Arctic (2005), relates that ‘Stories blow through you like the wind and roll over you like the sea. I’m finding that when you’re telling a story in the oral traditions, like my mother, they paint a picture' (Anchorage Daily News, November 8, 2005). Community Health Aides and Community Health Practitioners (CHA/Ps), the primary providers of healthcare in rural Alaska, share the importance of story as a culturally respectful way to create meaning and broaden understanding.

The story of cancer among Alaska Native people has changed dramatically in the last fifty years. As recently as 1950, cancer was considered a rare disease among Alaska Native people. Today, cancer is the leading cause of death for the many diverse Alaska Native cultural groups represented by the Athabaskan, Yupik, Cupik, Inupiaq, St. Lawrence Island Yupik, Aleut, Eyak, Tlingit, Haida, and the Tsimshian people. Cancer rates for Alaska Native people are among the highest of any ethnic group in the US and rates are increasing. Cancer death rates for Alaska Native people during 1998-2002 were 30% higher than rates in the US Caucasian population, while cancer survival rates were 17% lower than the US Caucasian population. Between the five-year period from 1969 to 1973 to the period 1999 to 2003, the rate for all cancers among Alaska Native people increased (34%) and for certain sites increased even more markedly: breast (23%), lung (14%), prostate (63%) and colorectal (24%) (Lanier et al., 2006).

CHA/Ps are the village-based providers of primary, emergency, and preventive healthcare in Alaska's 178 rural villages ranging in population from 20 to 1,100 people. CHA/Ps are selected by the people of their community, and over the course of two years participate in four, three-to-four-week intense medical training sessions. Because education for CHA/Ps must address a wide range of emergency and acute medical conditions, cancer-related topics are addressed throughout only two hours of instruction during their intensive basic medical training program. Cancer education for CHA/Ps grew out of their concerns for the increasing numbers of people experiencing cancer in their communities.
During cancer education courses, CHA/Ps share their traditional stories as well as their experiences of people living with and dying from cancer. As course participants tell their stories and experiences, stories of hope, stories of strength, and stories of resilience emerge. Additionally, cancer survivors are invited to speak with course participants and share their journey of living with cancer. The importance of learning from cancer survivors’ stories is highlighted by one CHA/Ps’ comment: ‘When I think about cancer I think of it as someone dying from it [cancer], after meeting with the cancer survivors I don’t think that much of cancer as death anymore.’

Stories can illuminate possibilities for healthy ways of living and being. ‘Indigenous people around the globe still tell ancestral stories to evoke healing spirits and inspire change’ (Meade, 1995, p. 1). Utilising storytelling to transmit educational messages is a traditional pedagogical method practiced by many American Indian tribes to share ideas and values (Hodge, Pasqua, Marquez and Geishirt-Cantrell, 2002). The use of story respects oral traditions of indigenous people. Most western societies view writing and reading as the foundation for civilization. However, in the article ‘Talking Leaves are Striped’, Warner (2003) contrasts western and indigenous cultural understandings. Zuni and Cherokee people characterise written and printed words as talking leaves that are striped, referring to written words as ‘...dead and dry, interrupting the process of listening, seeing, and understanding with the heart. Speech, however, is alive and moist, carried outward on the breath’ (Warner, 2003, p. 15). Reliance upon written words is thought to interfere with attention, interrupting listening, seeing, and understanding with the heart (Warner, 2003).

Our cancer education program for CHA/Ps in Alaska incorporates storytelling. Stories are woven into the fabric of cancer education courses to ground knowledge in culturally respectful pathways for learning. Courses are enlivened as participants share their stories and together create new stories. The hum of possibility permeates the air, energising the conversation. The use of story respects oral traditions of Alaska Native people. In May 2005, 293 (65%) of the 454 CHA/Ps responded in writing to a mailed cancer education survey. Of the 293 respondents, 240 (86%) were women and 239 (86%) Alaska Native people. Of the 278 CHA/Ps answering the question, ‘Do stories help you to learn?’, 97% (270) of the CHA/P respondents circled yes. By gender, 99% (228/231) of the female respondents and 87% (33/38) of the male respondents indicated that story helped them learn. Nearly all, 98% (224/229) of Alaska Native people and 93% (37/40) of non-Native people identified story as helping them learn.

To communicate effectively across cultures it is important to listen and hear each other’s stories. Storytelling plays an important role in a three-credit university audioconference cancer education course for CHA/Ps, ‘Cancer: Risks, Diagnosis and Treatment’. This distance telephone education course
connects people from diverse cultural backgrounds across Alaska’s 586,412 square miles, an area 1/5 the size of the continental US. Communities in Alaska are separated by vast distances of roadless terrain including majestic mountains, glaciers, tundra and rainforest, making travel challenging. During the course many diverse stories are shared, followed by a discussion in which meanings are explored. Themes such as courage, communication, listening, connections, community, healing, and spirituality emerge as stories are told and retold with new understandings. Written course evaluations reflect how CHA/Ps feel about story as a way to learn, as expressed in the following remarks.

- ‘Stories engage the heart and different parts of my brain.’
- ‘Stories are one of the best ways of learning. I think it feels more realistic.’
- ‘Stories give people something they can relate to, which causes a connection to what it is you are learning.’

The use of story embodies multiple spheres of learning as expressed by Alaska’s CHA/Ps. Stories create pathways for connecting people, facilitating knowledge and understanding, enhancing remembering, engendering creativity, expanding perspectives, envisioning the future and inspiring possibilities. Between May 2004 and April 2007, 13 week-long cancer education courses were provided for CHA/Ps, in five regional communities throughout Alaska: Anchorage (6 courses), Bethel (3 courses), Fairbanks (2 courses), Kotzebue (1 course) and Nome (1 course). There were a total of 104 participants including 89 women and 15 men, 89 were Alaska Native, 13 were Caucasian, 1 person was Hispanic and 1 person was from Africa. Of the 103 written evaluations that were completed at the end of the course, 99 respondents described ways that story supported their learning in response to the question ‘Do stories help you to learn? If yes, how...’. Only 3 participants left the question blank and 1 person wrote ‘no’. CHA/Ps, on both the end-of-course evaluations and the CHAP survey, wrote descriptions of their thoughts and experiences with how story connects people and facilitates learning in community. The following themes with representative quotes identify pathways for story-based learning as expressed by CHA/Ps.

Connecting people

- ‘We learn from everyday stories, learn from each other.’
- ‘Knowing, meeting, hearing others’ stories bring life to information.’
- ‘Sit, talk, listen, enjoy others’ company and stories. Stories are particularly valid in our culture.’
- ‘Stories give example. You can relate to them.’
- ‘...Makes you connect with the person.’
- ‘I’m fascinated with stories, especially from my eldest peers.’

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• ‘Stories from elders and other people help us learn in many different ways....'

Facilitating knowledge and understanding

• ‘...Because most of our culture uses stories to teach about life and behaviour.'
• ‘Also engages the heart and different parts of the brain than more literal lectures.'
• ‘I think it touches home more.'
• ‘...Helps to relate to whatever problem is being discussed.'
• ‘...Especially real life stories and experiences.'
• ‘Our culture uses stories to teach about life.' ‘As a Native American I learn through stories and pass knowledge through stories.'
• ‘Stories take me to that place—it gives me a deeper understanding.'
• ‘Stories bring more knowledge...give me the strength to spread the word of cancer and not losing hope.'
• ‘As a student you get participating with the story and consciously and unconsciously you’re learning at the same time.'

Enhancing remembering

• ‘I’ve listened to stories my whole life and I enjoy them and remember them.'
• ‘You can remember a story better than boring facts.'
• ‘Many leave a lasting impression. I tend to remember stories and experiences better.'
• ‘Hearing experiences – good or bad – can help in many situations.'
• ‘It’s lots of fun to listen to stories and it takes stories in you for a long time.'
• ‘It’s good to see, hear, and hear yourself, then it’s easily remembered.'
• ‘We learn new things everyday and what I hear I keep and next time I’ll know.'
• ‘Stories have a ‘something’ behind it!’
• ‘Good stories will stay with you.'

Engendering creativity

• ‘Stories make you think, imagine.'
• ‘You picture more in your brain and it sticks better.'
• ‘...Easier to visualise and learn and remember.'
• ‘We learn more by listening to others. It creates a picture and you remember.'
• ‘...Gives me food for thought.'
• 'There are a lot of different sides to stories.'
• 'Stories are never the same stories.'

**Expanding perspectives**

• '[Stories] give me a different knowledge or outlook on how people experience things.'
• 'Gives a clearer picture of how it relates to our own experiences and gives us a glimpse of other situations and experiences we may have later.'
• 'How others deal with their pain and loss.'
• 'How cancer has affected all of us in one way.'
• 'Hearing survivors tell their stories ...feelings, reactions, doing, and seeing how they helped other people or themselves with cancer. So I would have an idea how I’d approach and talk to patients with it [cancer]. Also with my family.'
• 'Stories help by showing us.'
• 'Good to learn from peers. 'Hearing other providers’ insight.'

**Envisioning the future and inspiring possibilities**

• 'Stories give me courage to go on in trying to support and help my patients as best I can.'
• 'Survival is possible and it is OK to laugh.'
• '[Stories] make me think and help me in the future if I encounter a similar problem.'
• 'Through stories you’ll know more next time, what to do or say.'
• '... Really opens your eyes to believing.'
• 'Real good story help you remember and want to tell others; spread the words, let’s help one another.'

Stories can offer guidance and wisdom, providing fresh insight. Similarly, stories can bridge cultural diversity, as the following additional written evaluation comments from cancer education course participants demonstrate:

• 'We as a class were able to share different traditions of Alaska and the lower 48.'
• 'Stories showed us how much we had in common, even though we were living in different areas.'
• 'Hearing how different kinds of Native people are going through the same problems and how they deal with problems helped me understand.'
• 'It helps you understand others’ culture.'
• 'Comparing and hearing stories from other places gives us ideas that may help us tackle and solve a problem. The more tools, the better.'

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Alaska’s CHA/Ps expressed the importance of story as a viable way of creating meaning and enhancing understanding. Stories offer a culturally respectful means to invite people to be active participants in a vibrant learning community. Stories invite action and choice by encouraging participants to critically reflect upon the possibility of diverse options. Through stories we begin with people’s knowledge, understanding, and experience and together build bridges to discover and explore possibilities.

During a course follow-up telephone conversation, a CHP described what was meaningful for her about the cancer education course,

‘...Touching base with the other Health Aides, hearing from everybody’s personal experiences, because [cancer] does hit just about everybody in one way or another. And like [another course participant], he said when he first came that he came because he was afraid of the word cancer and that’s why he wanted to learn. And I think all of us are like that until we see it and can deal with it and know that it can be turned around.’

Culturally grounded education sifts through the fertile soil of each person’s unique heritage to hear the stories of the many people who have journeyed before. Every person has a cultural heritage alive in the stories of their ancestors. As a cancer education course participant wrote on the end-of-course evaluation, ‘Learning about past experiences makes the information living and near. Gives it a heartbeat with hope.’ Through story we can become connected to the past in a dynamic process of embracing the present and creating the future. Story as described by Alaska’s CHA/Ps is a culturally respectful way to support their learning journey. By choosing to listen, to learn, to sow the seeds of visions, and to cultivate dreams, there is the potential to make a difference in the story of cancer among Alaska Native people.

References


Authors

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Spanish Abstract

Contar historias se encuentra en el conazón de ser humano. A través de las historias compartimos nuestros sentimientos, curamos heridas, aumentamos el entendimiento, fortalecemos la comunidad, y descubrimos la esperanza. Loretta Outwater Cox, nativa de Alaska y autora de El club de los contadores de historias, (The Storyteller’s Club) relata que ‘Las historias soplan a través de ti como el viento y pasan por arriba de ti como el mar. Encuentro que cuando estás contando una historia en las tradiciones orales, como mi madre, ellas pintan un panorama’ (Anchorage Daily News, 8 de Noviembre, 2005).

La historia del cáncer entre los nativos de Alaska ha cambiado dramáticamente en los últimos cincuenta años. Tan recientemente como en 1950, el cáncer era considerado como una rara enfermedad entre las personas nativas de Alaska. Hoy el cáncer es la principal causa de muerte de los diversos grupos culturales nativos de Alaska, representados por los pueblos Athabaskan, Yup ik, Cupik, Inupiaq, St. Lawrence Island Yupik, Aleut, Eyak, Tlingit, Haida, y los Tsimshian. La tasa de cáncer para las personas nativas de Alaska se encuentra entre las más altas de todos los grupos étnicos de EE.UU., y esa tasa va en aumento. La tasa de muerte por cáncer entre personas nativas de Alaska para el periodo comprendido entre 1998 y 2002 era un 30% más alta que la tasa de la población blanca de EE.UU., mientras que la tasa de sobrevivientes de cáncer eran 17% más bajas que las de la población blanca de EE.UU. Entre el periodo de cinco años entre 1969 y 1973, y el periodo entre 1999 y 2003, las tasas de todos los tipos de cáncer aumentaron (34%) y para ciertos sitios aumentó aún más marcadamente: mama (237%), pulmón (146%), próstata (63%), y colon-rectal (24%) (Lanier, et. al 2006). Ayuda para la Salud de la Comunidad y Practicantes de Salud de la Comunidad (Community Health Aides and Community Health Practitioners (CHA/Ps) son los proveedores del pueblo de cuidado de salud elemental, de emergencia y preventivo en Alaska en 178 pueblos rurales con una población de entre 20 a 1,100 habitantes. Los CHA/Ps son seleccionados por las personas de su comunidad y en el curso de dos años participan en cuatro, tres a cuatro semanas de intensas sesiones de entrenamiento médico.

Debido a que la educación para los CHA/Ps debe dirigirse a una amplia gama de emergencias y condiciones médicas agudas, los tópicos relacionados con el cáncer son abordados sólo durante dos horas de instrucción durante su intensivo programa de entrenamiento técnico. La educación sobre el cáncer dejó de ser una preocupación para los CHA/Ps en Alaska debido a la
aumentante cantidad de personas que tienen cáncer en su comunidad. Durante los cursos de educación de cáncer, los CHA/Ps comparten sus tradicionales historias así como sus experiencias de personas viviendo de cáncer y muriendo por causa de cáncer. Como los participantes del curso comparten sus historias y experiencias, historias de esperanza, historias de fuerza, e historias de resistencia emergen.

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