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Brief Report

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Culture Care of Individuals with Disabilities Teamed with a Service Dog

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Introduction

Representing the largest minority group today in the United States, over 61 million people are living with visible and invisible disabilities. While this group is diverse, within it is a community of those teamed with a service dog to help mitigate their disabilities. As a community, people with service dogs (i.e., service-dog team) share common lifeways, values, beliefs, and experiences of marginalization and discrimination that affect nursing care and require culturally congruent care. Yet, healthcare providers receive little to no education within their professional programs, or in their clinical workplace setting to support them in providing culturally congruent care to service-dog teams. Formed in 2016 and spearheaded by a nurse, Canines Assisting in Health (CAsH) strives to educate interprofessional healthcare providers to be knowledgeable about various types of assistance animals, and to be culturally competent in practice with individuals who have visible and invisible disabilities partnered with a service dog. The work of Captain Luis Carlos Montalván and his service dog Tuesday inspired its formation. As a disabled veteran of the Iraq and Afghanistan war, Luis became a national advocate for individuals with disabilities including those teamed with a service dog. Through his work, his own experiences, and those of others he gained understanding of the unique challenges service dog teams have in receiving healthcare. The philosophy of CAsH, grounded in the Social Model of Disability, recognizes that healthcare providers must be educated to support individuals to participate equally in society with those who do not have disabilities. Being teamed with a service dog allows these individuals to participate in society. CAsH, informed by individuals with disabilities teamed with service dogs, their families/significant others and an internationally accredited service dog organization, Educated Canines Assisting with Disabilities (ECAD, Assistance Dogs International Accredited), that breeds, trains and provides service dogs and ongoing support to this under-represented population, is focused on the teaching and learning of healthcare providers. Transcultural nurses can lead the way in providing and advocating for culturally congruent care for this community.

Globally it is reported that there are one billion individuals today living with visible and invisible disabilities. While the information presented in this article focuses on service dog teams in the U.S., service dogs are defined, acknowledged, and legally protected in many countries across the globe. Much of the information CAsH develops has international relevance and applicability. To this end CAsH welcomes international and national colleagues who see the importance of this work and would like to join our army of advocates as CAsH Champions.

Culture Care Theory

Nurses have an important role with individuals living with disabilities who are teamed service dogs. Across health care delivery settings nurses have broad influence on patient care, both advocating and actualizing quality care for all, and especially for vulnerable marginalize groups. Leininger's Culture Care Theory (CCT), begun in the 1960's with the first textbook published in 1976 [1], continues to be developed and supported through research [2]. The CCT is a valuable framework for providing culture care for individuals living with disabilities who are teamed with service dogs.

The purpose of the CCT is to be curious about care and its interdependence with cultural phenomena. This curiosity begins with awareness of similarities and difference that distinguish culture in its various forms. Awareness can lead to learning about cultural phenomena in order to know and explain the interdependence of care and culture for different cultural groups or communities. This understanding supports providing culturally congruent care for individuals living with disabilities who are teamed with service dogs through decision and action modes to provide culture care. According to one of the major theoretical tenets of the CCT in caring for those across cultures, culture care value, beliefs, expressions, and patterns must be known and used appropriately, sensitively, and meaningfully for care to be culturally congruent and therapeutic [2].

Luis Montalván in his memoir, *Until Tuesday: A Wounded Warrior and the Golden Retriever who Saved Him* [3], and in his international advocacy and public speaking engagements shared what it was like to have been a very abled soldier, to becoming a very disabled veteran. Following his honorable discharge from the military, he found himself living with the realities of a traumatic brain injury, various musculoskeletal injuries which eventually led to an above the knee amputation, and complex post-traumatic stress disorder. Luis recognized that he was not doing well. He was experiencing severe symptoms and self-medicating with alcohol, and he worried that his care plan was not providing enough support and that without additional intervention he would drink himself to death. Fortunately, he was offered the opportunity, by ECAD (ecad1.org), to be teamed with a service dog and he thought and hoped that this would be an important addition to his care plan. After qualifying and completing training he was teamed with his service dog, Tuesday. While he experienced challenges in receiving the care he needed before he was teamed with Tuesday, his challenges were compounded when he returned for care with a service dog. It was hard for nurses and healthcare providers who listened to Luis speak to hear that the challenges he experienced came from his healthcare providers and was due to lack of knowledge. This led Luis to say on behalf of himself and others in this cultural community, “When it comes to those of us with service dogs, health care providers tend to be reactive instead of proactive,” [4]. *Canines Assisting in Health* was inspired by the awareness that for nurses and other healthcare providers to be proactive rather than reactive in providing care to individuals living with disabilities who are teamed with service dogs, they need to have the knowledge to understand the interdependence between this cultural community and their needs to support culturally congruent care.

What is a Service Dog?

A service dog is a working dog and comes under the category of Assistance Animals. A person with a visible and/or invisible disability is teamed with a service dog to help mitigate their disability through the service dog performing a task or tasks that allows the person independence and the ability to live in society with those who do not have disabilities. In the United States the Americans with Disabilities Act gives the right for a person with a disability who is teamed with a service dog to be accompanied by their service dog wherever the public is allowed. According to the ADA a service dog works for an individual with a disability other than blindness or deafness and must be trained to take a specific action, or task, when needed to assist the person with a disability to mitigate the needs of that person.

There are several options for task training a service dog, including self-training, training by a professional dog trainer, or training the dog to the rigorous standards of a service dog organization that is accredited by an external organization, such as Assistance Dogs International. Regardless of the method of training, all service dogs have a required standard of behavior to be in the public domain. The basic standard requires the dog to be: under the control of the handler at all times; housebroken; and collared or harnessed, and leashed unless this restricts the service dog’s work. While it is beyond the scope of this article to fully address Assistance Animals, and specifically service dogs, readers are directed to a previous publication on this topic [5].

Defining Service Dog Teams as a Cultural Community

In working with Luis Montalván and Tuesday, and numerous others who are teamed with service dogs to mitigate their disabilities, anecdotally they have shared their experiences and offer a beginning understanding of the cultural community of service dog teams. People with disabilities are currently the largest minority group in the United States. There is great diversity with types of disabilities among the 61 million people living with disabilities. It is often identified that this great diversity of disabilities makes it difficult to define a culture of disability. Nevertheless, within those with disabilities some are fortunate to be teamed with a service dog to help mitigate their disabilities. A community can be defined as individuals who share values, assumptions, and beliefs. As such, these individuals can be identified as a cultural community as they share values, assumptions, and beliefs about service dogs and share the experience of being teamed with a service dog. Individuals teamed with a service dog assume that dogs can be trained to assist humans, believe a service dog can mitigate disabilities, and value the tasks that service dogs perform to help individuals with visible and invisible disabilities. Members of a cultural community have common needs, and understanding those needs is essential to the provision of culturally congruent care.

Service dog teams need healthcare providers to be knowledgeable in several key areas in order to provide them with culturally congruent care. These key knowledge areas include: communication; the social model of disability; the Americans with Disabilities Act; the different types of assistance dogs with a focus on service dogs; healthcare organization policies on assistance dogs; zoonosis/infection control/ animal welfare; and, rites of others in contact with the service dog team, including those in the environment who have severe dog allergies or phobias.

Learning from Service Dog Teams

Members of the cultural community of service dog teams anecdotally identified some key behaviors they would like healthcare providers to practice and support when they are receiving care (Figure 1). As identified the information at this time is anecdotal and comes from conversations and discussions since 2016 with individuals with disabilities teamed with service dogs, as well as information from the Americans with Disabilities Act, Assistance Dogs International, and various written sources of information about the experience of receiving healthcare when teamed with a service dog. The goal is to use what has been learned to guide the development of a survey for individuals teamed with service dogs to continue to build on this understanding, and to gain additional insights for the care of this cultural community.

What Service Dog Teams Say They Need from Their Healthcare Providers in Their Interactions

Dear Healthcare Provider,

Please

- communicate with me, ask me what my needs are, I am an expert in this
- know that my service dog and I are a team, my service dog mitigates my disability and lets me be independent and interact in society
- make me, not my service dog, the focus when I am receiving care
- know that it is okay to acknowledge my service dog, to me, but,
- do not interact with my service dog without my directing the interaction- this can lead to distractions and can cause me and my service dog to be unnecessarily stressed and potentially injured
- do ask me where my service dog will be most comfortable and out of the way during my care
- review your healthcare organization's policy on assistance animals
- advocate for me and my service dog should this be needed, my service dog is an integral part of my care plan, we need to be together as legally protected by the Americans With Disabilities Act

Figure 1: Learning from Service Dog Teams.

Communication is essential for all healthcare interactions, including working with service dog teams. Overall healthcare providers are well-educated, competent, and knowledgeable about what they have learned. If a healthcare provider lacks knowledge of the cultural community of service dog teams this can lead to them being frustrated and can compromise communication. True communication is two ways and involves the basic model of communication which is simple and includes both verbal and non-verbal interaction around the message, between the sender and the receiver. Yet, there are many things that can get in the way of the message being sent, received and responded to. Healthcare providers need to be aware of facilitators and barriers to communication with patients. This includes being reflective of one's own communication practices and respectful of different challenges patients may have in communicating.

Observing service dog teams should be coupled with communication. Though observation healthcare providers can come to know and understand the unique and essential relationship between human and canine. Observing service dog teams can help healthcare providers appreciate the work the service dog does to mitigate the disability. This can be seen in what is required of an individual as the handler of the service dog in giving commands or cues to the service dog for the service dog to execute and perform the task(s) as an extension of the person. A simple example is the service dog learning the basic command "Tug", this command can be translated into many tasks especially with adapting the environment. By putting a tug rope on a door, the dog is then given the command to "Tug" and as trained the dog can perform the task of opening the door for the person. The dog may also be taught words for different situations in which they will be asked to "Tug", such as "Open," and can then be directed with "Open" when the task is to tug and open the door. Communicating with and observing service dog teams will help support learning the interdependence of care and culture for the cultural community of service dog teams.

Canines Assisting in Health

Since 2016 Canines Assisting in Health (CAsH) has been educating interprofessional healthcare providers to be knowledgeable about and culturally competent in caring for service dog teams. Simply put, CAsH supports individuals with disabilities teamed with service dogs by educating their healthcare providers. This education is offered in a variety of ways, including masterclasses, workshops, simulation videos, discussion groups, demonstrations, and case studies, across the domains of learning, cognitive, affective, and practical. The goal is to increase the confidence of healthcare providers in working with the cultural community of service dog teams. To date, CAsH has educated thousands of healthcare professionals who consistently identify and acknowledge the importance of this knowledge to the care of current and future patients, as well as sharing this important information with other healthcare colleagues.

To expand this work CAsH has complete its *Big Shakes Little Shakes* program to train those interested in championing this knowledge. The *Big Shakes & Little Shakes* title represents exactly what it means when a service dog gets the command to “Shake” with you. Shake is an appropriate introduction, with the handler, the person teamed with a service dog, directing the service dog’s behavior in a controlled way. This aims at preventing distraction that could cause injury to them and/ or their service dog. *Big Shakes & Little Shakes* introduces those in healthcare to the cultural community of individuals with visible and invisible disabilities teamed with a service dog to support quality care. Content supports learning across all three domains of learning, cognitive, each of the key knowledge areas previously identified.

Expanding the education of healthcare students, clinicians, staff, and administrators, to be knowledgeable about and culturally competent in providing care to individuals with visible and invisible disabilities teamed with a service dog, is the aim of this program. Healthcare professionals who are committed and able to champion quality care with this cultural community of patients within their education or practice setting will receive training, materials, and coaching, to put this education into practice.

The Program offers the CAsH Champion Trainer many options to tailor learning to their audience, and time available. CAsH developed and produced three simulations based on real healthcare experiences of individuals teamed with service dogs. These individuals led script development, and are featured in the films, along with other actors who work with CAsH educational programs, at the College of Health Professions, as standardized patients. Four interviews were also developed and produced to let individuals teamed with service dogs share some of their experiences. Each offer insights on living with visible and invisible disabilities, being teamed with a service dog, and, experiences in public and healthcare. Big Shakes modules include all full-length simulations, and interviews. Little Shakes modules have been constructed from selective segments of the simulations. The CAsH Champions Train-the-Trainer guide provides a learners’ outcome come table identifying key knowledge areas and objectives for each across the domains of learning. Suggestions for pause-and- reflect teachable-moments, and reflection and discussion questions to support learning are provided. Additional supporting materials, readings, websites, and resources completes the Big Shakes & Little Shakes program.

Nurses have a wide range of influence within healthcare, would you like to be a Canines Assisting in Health Champion? Please be in in touch if you would and join our army of advocates, canines-and-health@pace.edu

Conclusions

Luis Montalván said, “It’s hard to be a service dog, just like it’s often hard to be disabled...Please always respect service dogs and the people who need them” [4]. These words remind us that providing culture care to service dog teams must begin with respect. Service dog teams have unique relationships, grounded in the human-animal bond.

Canines have been assisting in human health since ancient times. The role of a service dog over time has become defined, acknowledged and legally protected. While a service dog may not be appropriate for all individuals with disabilities, for those who can benefit from being teamed with a service dog, like Luis Montalván, a service dog may be considered a non-pharmacologic intervention. It is imperative that healthcare providers be knowledgeable about and culturally competent in caring for service dog teams. While there are over 61 million Americans living with disabilities, only 500,000 are teamed with service dogs. Clearly, more individuals living with disabilities can benefit from an assistance dog to mitigate their disability and support their independence. Educating healthcare providers about this valuable resource is an important step in advocating for patients with disabilities. In addition to be a leader in providing this education a next step for CAsH is to turn the anecdotal information learned from service dog teams into research evidence. To this end a national survey with several accredited service dog organizations is planned to validate what has been learned anecdotally and to gather more information about the needs of the cultural community of service dog teams when receiving healthcare.

Acknowledgements

In loving memory Capt. (Ret USAR) Luis Carlos Montalván (1973-2016) & Tuesday, ECAD Alumnus (2003-2019) Be a CAsH Champion: Join our Army of Advocates. Contact: Canines-and-Health@pace.edu

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