The Power of Words
What Can We Learn From the Disabilities Movement?

“As names have power, words have power. Words can light fires in the minds of men. Words can wring tears from the hardest hearts.” (Rothfuss, 2007, Chapter 86)

I have always enjoyed the power and beauty of words, hiding fiction books under my text books so I could read during school hours. But it wasn’t until I became a nurse and mother that I really understood the power of words we use in health care and the importance of language in health care that puts the person first.

It was 1998. I had been a nurse for 12 years, board certified in gerontology since 1990, and had just begun my career researching ways to improve the care of individuals with dementia and delirium. I was aware of issues with language in the care of older adults and the work by Robert Butler on ageism, and in some of my own work, I was writing and lecturing about the stigma of being labeled by disease. But like many, I still used words such as “diabetics,” “addicts,” and “epileptic.” My grants and papers used the phrase dementia patients when talking about who I would enroll in my studies if they were funded. This changed in December 1998 when my son, who had been born in June, was in an academic children’s hospital.

The facility where my son was admitted was less than 1 year old and very beautiful. It had an entire wall in the lobby that was an aquarium and light-filled rooms with space for families to be at the bedside. The architects and family council had given months of attention to making the physical environment child- and family-friendly. The facility had friendly child life specialists who would come in and play and interact with ill children. Overall, I thought it was a progressive facility with an impressive physical environment.

My son, who was 6 months old, was in the hospital with pneumonia. One morning I had been sleeping on the couch in his room, and the resident walked in with a group of students. I was an assistant professor in the school of medicine department of internal medicine at the time, so many of the faces that came into the room were familiar to me. The chief resident (who I knew from my work) walked in first, followed by other residents and medical students. He stopped at my son’s bed, which was an oxygen tent crib. Without addressing me, he stood in front of the crib and began talking about my son using these words: “This is a Down’s kid. Down’s kids often have issues like this.” He went on to discuss the percentage of these children who have respiratory and cardiovascular problems and talked for several minutes about children with Down syndrome having low muscle tone and developmental delays, problems with reflux (which my son was having), etc. He went on for what seemed like forever, but was probably only...
5 or 10 minutes, talking about all the problems that could occur in children with Down syndrome, addressing only the medical students and residents. He did not refer to my son by his name or address me, but he named my son “a Down’s kid.”

Finally, the chief resident paused and I stood up from the couch/bed and introduced myself, saying:

I know you’re teaching the medical students and I’m grateful we are here being cared for in this children’s hospital, but please think carefully about your words. My son is not a Down’s kid. He is a son, a nephew, a cousin. He is a new baby interacting with his environment, loving his family, being held by his parents, loved by his nieces, aunts, and grandparents. And yes, he has Down’s syndrome, but that’s not what he is. He’s a little boy who is very sick and in the hospital. Please do not call him a Down’s kid.

I cannot remember what else I said or he said in return, although I do not recall him getting mad. I think he was astounded and shocked that I had confronted him in the room at that moment and I can still recall how my heart was pounding in hearing him refer to my son as a Down’s kid.

I now know the preferred terminology is “a child with Down syndrome,” and since that time I have learned a great deal from the disabilities movement. Perhaps I should not have done it there, but I wanted the students to understand the power of language. I wanted them to know from a mother that people are people first, defined by their relationships, individual personalities, desires for purpose in life, and their ability to love, engage, and interact with others, all things my son is able to do.

My son, William, has Down syndrome and just turned 18 years old. He also has diabetes and other endocrine disorders, but in every other sense he is just like everyone else without these conditions. (Down syndrome is a genetic condition, not a disease). He wants to be loved, have important fulfilling relationships, have a job (at 17 he was working in a print shop at his high school), and be productive. A few months ago he told me at bedtime while reading, “Mom, please help me go to college.” He is hardworking and motivated, and yet because of his condition, and in this case, because his condition is so visible in the way he looks, people often label him first by his Down syndrome and fail to see his strengths.

A similar situation occurred approximately 10 years later when William was diagnosed with diabetes. People would repeatedly say, “He’s a diabetic. We have to do this or have this…because he is a diabetic.” And I would have to speak up and say he’s not a diabetic, he’s a person with diabetes, who actually manages his own disease very well. He checks his own blood sugar. He understands his diet better than I do my own, and he is a young adult who happens to have diabetes and Down syndrome.

That early experience and living in the world of disabilities has helped me think differently about my own work with individuals with dementia long before person-centered care (PCC) was emerging as a strong force in practice and research. Individuals with dementia may also have a look or deficits that make others define them primarily by their disease, limit what is socially acceptable to do, and list all of the things they are unable to do or at risk for, such as falling, delirium, financial abuse, loss of decisional capacity, and loss of relationships. After that defining moment and as the years went by, I became acutely aware of my own use of language in health care. I began to look at the places in my own writing in papers, grants, or lectures where I would use the words “demented patients.” As an editor, I still see this commonly in writing that I review. This choice of words happens with strong writers and rigorous scientists who are used to this as standard language in health care. I see this on a weekly basis in the hospital setting where I conduct clinical research and nurses or physicians give report by first saying, “She is demented.” As a cognitive health researcher and clinician, I believe knowing and communicating the diagnosis of dementia or cognitive impairment is important (Gerontological Society of America Workgroup…, 2015), but emphasizing the person first is also part of humanizing diagnosis and care.
What can we do, as bedside nurses, interdisciplinary health care professionals, researchers, and policymakers, to improve the use of words for individuals with dementia and disabilities? We can understand the power of words, speak up when we hear words that label or hurt, and advocate collectively for the power of words and the power of PCC. Nurses can reflect on instances in their own clinical care of older adults when they use words that do not put the person first. When colleagues ask me to review their work for the science and I find words such as dementia patients, diabetics, etc., I help them see a better way to use their words (i.e., individual with dementia or diabetes) and to consider their problem or program of research from the perspective of the person first. I also use language to tell about real people with dementia trying to live well with their disease — to illustrate with stories what it is like to be that individual with diabetes or Down syndrome or dementia — and to reframe it as living positively with a disease or condition. Despite my starting this editorial with a negative experience with my son with intellectual disabilities, much can be learned from individuals in the field of intellectual disabilities who consider and engage the individual first and have many more years of experience weighing the risk of things such as falling or failing to focus on the individual’s priorities and values while trying to balance autonomy, dignity, and safety.

We should borrow from the field of intellectual disabilities research and practice where they have been using person-first language, community engagement, and person-centered planning to transform the field and care for individuals with disabilities for more than 10 years (Kaehne & Beyer, 2014). The intellectual disabilities community has had an international campaign to update their language and end the use of certain words (e.g., mental retardation) since 2004, highlighting this work on national television and during the Special Olympics (access http://www.r-word.org/r-word-history-campaign.aspx).

Nurses should become familiar with the current literature on PCC and the power of language, including the American Geriatrics Society’s (AGS; AGS Expert Panel on Person-Centered Care, 2016) definition and essential elements of PCC; work in the United Kingdom with Murna Downs and others to define PCC and enhance care for individuals with dementia (Fortinsky & Downs, 2014); and work by Williams, Herman, Gajewski, and Wilson (2009) on communication and behavior in older adults. We can educate caregivers on ways to integrate the elements of PCC in their day-to-day care.

The Journal of Gerontological Nursing has a section led by Dr. Kimberly Van Haitsma that tackles many of these challenging issues to improve PCC. When we teach or interact with future nurses and health care professionals (like those medical students in 1998), we can use our powerful words for knowledge and healing instead of cultivating stigma and labels. We can conduct research that engages older adults and individuals with dementia to define and better understand PCC across care settings where resources are scarce and it can be more challenging to implement.

That day, now almost 18 years ago, I was not feeling very powerful. My son was sick. He had oxygen levels in the 70s. I was scared and sleep deprived. I was worried about him. Perhaps in 1998, because of my work in gerontology and connection with individuals with dementia, I was able to speak up about the power of words. I challenge you to have the courage to do the same as a nurse, health care professional, and family member or caregiver.

We can and must use our words to heal and connect to the individuals in our care regardless of condition.

REFERENCES


Donna M. Fick, PhD, RN, FAAN, FGSA
Editor

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