

# 2019 Online KT Conference: Innovative KT Strategies That Work

Hosted by AIR's Center on KTDRR

October 28, 30, and November 1, 2019

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■

# Misinterpretation, Misunderstanding, Misdiagnosis

Seeta Ramdass

Seeta Ramdass Consultants; McGill University  
Health Centre Users' Committee; Community Health  
Montreal

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■

# Misinterpretation, Misunderstanding, Misdiagnosis

Responding to the acute and under-recognized difficulties people from sociocultural and marginalized groups with complex social needs face in accessing health and social services can be very challenging and potentially harmful. Social, cultural, religious, and language barriers can often lead to misinterpreted information, inaccurate conclusions, misunderstandings, and misdiagnosis. This presentation will engage participants in an interactive fashion to better understand the importance of addressing social and health care needs within a comprehensive sociocultural context.

# Kalim (1)

Hello: I am a 76-year-old male patient named Kalim. I have a history of diabetes, heart disease, and hypertension. I immigrated here in my 20s, so I have lived here and contributed to this society for 50 plus years. I come from a family of 10 children; we were poor, food was scarce, and medical care even more so. I am one of the first members of my community and the first member of my family to immigrate here from Andhra Pradesh. My mother tongue and customs are Telegu.

# Kalim (2)

When I got my first apartment here and found some steady employment, I was able to sponsor some family and friends. People from my village and area eventually moved here over several years. I put them up in my apartment until they could support themselves. They eventually rented in the same apartment building and sponsored some of their family and friends too. After just a few years, members of my community had moved into my building and other buildings next door.

# Kalim (3)

I eventually started a business here, a small grocery store that grew from selling local goods to foods and products from my culture as well. I was able to provide culturally familiar foods and products to my community and introduce new items to the locals. Everyone could shop in my store and find things of interest and need.

# Kalim (4)

I employed over 40 people full time, which meant all these people had an income and were able to sustain their families and their communities. My employees came from different backgrounds, but most were from my own culture. With the help of my community and the generosity of my customers, I raised money to buy and renovate an old dilapidated building into a small temple for our community to worship, to gather together to celebrate, to mourn, and to heal. The temple was not just a place where we worship; it was really our community centre, our school, and our clinic.

# Kalim (5)

I was no longer alone; my community was growing and evolving around me. I was at the centre of my community. They counted on me to help them get settled, learn their way around, and adapt to their new country while still maintaining our cultural values. I did what I could to preserve my own heritage while adapting to the wonders and privileges of my new home and living in harmony with my new neighbours in my new country.



# Kalim (6)

The people of my community view me as an elder and founder of our community here. They look up to me and expect me to lead them, advise them, and care for them. They depend on me, and I cannot let them down. I must be strong for my community as an elder. I practice and teach the ways of our customs, using the healing herbs and rituals of my ancestors, conducting the prayers and special religious life and death ceremonies of my heritage. As a leader in my community, I have many roles: father figure, advisor, teacher, and healer. I cannot be frail or weak or let my people down.

# Kalim (7)

I had a cardiac bypass procedure last year. I tried to hide this from my community, but they found out anyways since I was absent from my business, community events, and the temple. Since then, I have lost my wife suddenly and unexpectedly. She was a warm, caring person who helped me run my business from day 1. She helped me to care for our community and preserve our traditions. Her sudden loss has been difficult for me to deal with and has been hard on our community.

# Kalim (8)

Now I am too old and sick to run my business, so I retired. I lose my balance often, and I have joint pain, especially in my hips. I had hernia surgery a week ago. I was discharged from the hospital the next day despite the fact that I was feeling dizzy and in pain. They gave me pain medications and sent me home. One day after being discharged, I fell in my house and split my head open. There was a lot of blood. I don't remember much after that. My younger daughter took me to the emergency room. They asked me if I had pain, and I shook my head from side to side. They said "good." They asked me if I felt dizzy, and I shook my head from side to side; they seemed pleased.

# Cultural Broker/Navigator

Hi, I am the **Cultural Broker** or **Cultural Navigator**. I just met this patient. He is of Telangana background. In this culture, shaking of the head from side to side means Yes—not No as in North American culture. He is from the Brahmin caste of his culture, which means that his people view him as a teacher, religious leader, and protector.

# Shanta

Hello, I am **Shanta**, the daughter and caregiver of the patient. I need help to take care of my father who is very frail; he has heart disease and diabetes. I have been trying to get this help since last year after he had heart surgery. I don't really know how to take care of him, and I am scared to lose him. I did not learn to take care of the sick. My mother died suddenly so I never learned to take care of the sick. I need someone to check my father because he is getting old and I do not know how to take care of him, yet I have to take very good care of him because it is my duty as a daughter to him and a duty to my community because he is an elder and leader and of Brahmin caste.

# Cultural Broker/Navigator (1)

The daughter, Shanta, has been trying to get a geriatric assessment for her father. Because she is the only daughter in the family, she is responsible for her parents. And because of her father's prominent role in the community, she must devote herself to his needs.

# Cultural Broker/Navigator (2)

She only completed high school and then she had no choice but to help her parents by working in her father's store. She has no personal health insurance coverage and is unaware of this need or her own personal needs other than she must care for her father.

# Cultural Broker/Navigator (3)

She is rather isolated because she is devoted to doing everything for her father: caring for him and coordinating his schedule for his important role in the community. She is not used to asking for or receiving help as she has fallen into the primary female nurturer role, especially since her mother died. Furthermore, in this culture there is a general reluctance to ask for help, especially for an elder who is a leader—for fear of appearing disrespectful.



# Shanta (1)

Hello, I am **Shanta**. I care for my dad full time. It is exhausting work, and I am close to burning out but there is no support for me. I have never told anyone before about how tired and stressed I am. I have no medical or nursing experience, but I have to push through and do what I can for him. I use our traditional spiritual and healing practices to help my dad, but this is not enough. His medications and cost of living is very expensive and impossible to be covered by his small pension and insurance. I am still waiting for someone to help us to get the materials he needs to navigate around the house (the shower and bath, etc.) because he has the tendency to fall. He needs a walker or a wheel chair because he cannot walk or stand for too long, but he does not want them.

# Shanta (2)

He had hernia surgery last week. He was discharged a day later despite my concerns to the medical staff that he is on blood thinners and is weak and wobbly. When we got home, he said some confusing things as though my mother was still alive. He called out for her. He also had an episode where he sat very still and speechless for close to an hour. He fell in the house while trying to get up to go to the bathroom and split his head open. I called an ambulance, and we went back to the hospital where he had his hernia surgery 2 days ago.

# Shanta (3)

He waited for 4 hours before having a CT scan. We were told he had a brain bleed, but since he could speak and confirm his name and that he had no dizziness or pain, they sent him home. I know my dad best, and I told the medical staff that some of his behaviours earlier were not normal and that he was confused. I called his family doctor and his cardiologist; they said he should be kept and monitored at the hospital because he is on blood thinners. I told them that the emergency room staff discharged him and simply told me to call 911 if he got worse.

# Shanta (4)

As his caregiver, I was not allowed to be in the room when he was being examined and questioned by the hospital staff. I know he is dizzy and has pain, but somehow the doctors think otherwise and sent him home. I do not understand why. I am worried about what could happen to him at home, and I am not qualified to care for him or know what to do if he got worse.

# Cultural Broker/Navigator (1)

A social and clinical assessment of the patient and his family environment is urgently needed. It would be helpful to have some home care arranged as well as some financial assistance, especially since the daughter is the only full-time care giver that the father and the community trusts her with his care.

# Cultural Broker/Navigator (2)

The Telegu nonverbal way of communicating the word “yes” is to shake the head from side to side. Kalim, when asked if he was in pain and dizzy, shook his head side to side to confirm that he was in fact dizzy and in pain. However, this action was not interpreted in the context of his culture, but rather in the context of the clinician’s culture rendering it a gross misinterpretation of the actual response of the patient: The clinician thought that Kalim was not in pain and he was not dizzy.

# Cultural Broker/Navigator (3)

In this culture, it is very important for Kalim to show his community that he is still autonomous and strong, especially since he plays many roles: elder, leader, advisor, and healer. In his culture, it is inappropriate for any woman outside the family to care for him, and his community is not comfortable asking for help from those outside the community—especially for him—because in asking for help for him they may appear to be disrespecting him, a very offensive thing to do to a Brahmin in the culture.

# Shanta (1)

My father does not want to have anyone else care for him but me. The community does not want anyone else to care for him but me. He is not comfortable with strangers caring for him. He wants to show he is still able to take care of himself and the community and that he is still strong.

In our culture, it is inappropriate for any woman outside the family to care for him. He does not want to get financial assistance because he must show he is independent; all this is necessary for his self-esteem and to fulfill his responsibility as an elder in our community.



# Shanta (2)

I would like to help maintain his dignity and preserve his status in the community. It is important to him, especially since my mother died. It is also very important to the entire community that he is kept close to them.

As the only daughter in my family, it is my duty to support and care for my father. It is my honor and privilege to care for my father. Personal desires and wants are not important in my culture, only fulfilling my duties to a highly respected community leader who happens to be my father.

# Shanta (3)

It would be very helpful if I could be trained to be a professional caregiver so I do not have to ask for outside help to care for my father. I can do it all myself, which will make him happy, is better for his morale, and is expected of me by him and the community. I never had the chance to learn beyond high school, and I would like to learn to provide care to others in a professional way.

# Cultural Broker/Navigator

We have to help the patient with his disabilities, but we also have to help the caregiver. She needs support and training.

# Union

Hi, I am the **Union**. I have another perspective: If we start compensating and training caregivers, then we will lose jobs in the health care network.

# Logic

Hi, I am **Logic**. We should have transition care units, rehabilitation units, step-down units, and more community-based long-term care places to help elderly patients get back their autonomy. These should be culturally safe and sensitive environments located within the patients' communities to keep them in familiar neighbourhoods surrounded by community members who can play different care-giving roles and sustain this patient more efficiently. If we do this, then it may help prevent them from relapsing and ending up in the Emergency Department and occupying acute-care beds with their long-term needs. It will be good for their morale, and the assistance and participation of the community in the care of the patient may also save the health care system money.

# Hospital Administration

Hi, I am the **Hospital Administration**. Our Emergency Department is bursting at the seams. Wait times exceed 15 hours. We have many elderly patients who need complex care. Our acute-care beds are congested with many of these elderly patients because there are not enough beds in the community to take them. It is challenging to admit more complex acute-care patients if we cannot liberate our beds of long-term care patients. Having socioculturally safe and adapted environments is important but is not a priority right now—acute care is.

# Health and Social Services System

Hi, I am the **Health and Social Services System**. Creating culturally safe and sensitive transition care units, rehabilitation units, step-down units, and more community-based long-term care places for the elderly is a nice idea, but it is not a priority right now. That is a very resource-intensive and cost-prohibitive task! I will need human, material, and FINANCIAL resources to inject into this task! This will take time.

# Time

Hi, I am **Time**. I have been observing this phenomenon for over 30 years. This is an old and worn-out excuse that many previous bureaucracies have used. Over the past decades, I have seen numerous migrations of various cultural groups into our country. I have seen millions of patients and their families go through similar situations like this. It's the same old story. We have become a more socioculturally diverse society with hybridized cultures among us. This trend will continue.



# Logic and Innovation

Hi, we are **Logic and Innovation**. The government, bureaucrats, etc. are complaining about resources. Well, why not recycle some of the abandoned health institutions you already have? Some of them are already adapted for patients with physical and mental challenges. Why not use medical, nursing, and allied health professionals-in-training to staff these facilities? Why not engage more cultural brokers or cultural navigators in the multidisciplinary teams who care for patients? It would save lives and improve the quality of life. Oh, and why not use technology such as digital games, videos, etc. to help treat and improve patients' autonomy and functionality?

# Society

Hi, I am **Society**. There are more people in this country over the age of 55 than ever before. Data from the 2011 census showed for the first time that there were more people aged 55 to 64, typically the age group where people leave the labour force, than aged 15 to 24, typically the age group where people enter it. These older people contributed to building our great country. They served our communities. They want to continue to be active and involved as they age. Why are we not better prepared to help them have a healthy old age, instead of just letting them age? We can enable them instead of sustaining their disability or inability.

# Coroner

Hi, I am the **Coroner**. While all this has been going on, the patient and millions more have died. Miscommunication and misunderstanding played a role in his death. There is a need to implement socioculturally safe and sensitive measures to manage the socioculturally complex barriers to health care that exist in our very diverse society. We need support and action by those with the power to implement change and preserve the health, well-being, and dignity of all patients from all backgrounds.

# Disclaimer

The contents of this presentation were developed under grant number 90DPKT0001 from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

Don't forget to fill out the evaluation form!

 [www.ktdrr.org](http://www.ktdrr.org)

 [ktdrr@air.org](mailto:ktdrr@air.org)

 4700 Mueller Blvd, Austin, TX 78723

 800.266.1832

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■