

Special Article

## **Patient and Family Centered Care from a South East Asian Cultural Perspective: A Discussion**

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### **Abstract**

Patient centered care is putting the patient and their family as the focus of care and making them active members of the health care team. Although, research has shown that patient and family centered care (PFCC) yields better outcomes, it is still being met with resistance since major changes should occur which are shift in focus from physician to patient and policy changes. In South East Asian countries like Thailand and the Philippines, PFCC is affected by cultural and socio-economic factors. These factors either enhances PFCC or diminishes it. This paper explores the insights and accounts of the researchers about PFCC in their home countries and tries to compare it with how it is being done in the US. Three questions were asked in order to understand PFCC. 1) What are the principles and practices of patient and family centered care? 2) What are the approaches for implementing a model of patient and family centered care in the practice setting? 3) How to measure whether or not such a model would improve care processes and patient outcomes?

**Keywords:** Patient centered, South East Asia, Thailand, Philippines

### **The principles and practices of patient and family centered care**

When patients visit a hospital or a clinic, most of the time they feel like they are just paying for a medical service. They are just one of the customers with health issues or needs that are being treated by physicians and nurses. Patients are not in control of their treatment in any way. Physicians make all the decisions while patients and their families are not 100% informed of their diagnoses, treatment options and prognoses. This is the traditional way of how a patient receives health care. When a hospital places patients at the center of their focus, instead of putting physicians first, patients and their families can feel the changes. When everyone focuses on patients and take them as active members of the health care team, developing care plans, and making decisions together with patients and their families, patients will feel that they are respected

and engaged, their voices will be heard and they are truly part of their health care “team”. This is the essence of the patient and family centered care (PFCC) (Institute for patient and family centered care, 2009).

The Institute for Patient and Family Centered Care (IPFCC) (2009) defines “Patient and Family Centered Care” as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families”. PFCC practice engages patients and their families as active members of the health care team, which means patients and their families are involved in every aspect of the health care process. In a PFCC model, patients/families and the health care providers (Doctors, NPs) are partners and team members with the common goal of providing quality

health care to the patient with the best possible outcome (Reid Ponte, 2013).

Dr. Pointe (2013) has summarized the principles of PFCC as follows: “1) People are treated with dignity and respect. 2) Clinicians, researchers, and staff communicate complete and unbiased information to patients and families in ways that are affirming and useful. 3) Patients and families build on their strengths by participating in experiences that enhance control and independence. 4) Clinicians and staff prioritize knowing the patient and family while developing therapeutic relationships over time to assure coordination and continuity in the care delivery experience. 5) Collaboration among patients, families, clinicians, and staff occurs in the delivery of care as well as in the work of institutional policymaking, program development, and professional education.” (Reid Ponte, 2013). Research has shown that PFCC practices have led to better clinical outcomes (Pollack& Koch, 2008; Stewart et al, 2000; Reid Ponte & Peterson, 2008; Rickert, 2012; Frampton, 2008), but in reality, there are still a lot of resistance in hospitals and clinics. That is happening because in order to implement PFCC, two fundamental changes have to happen: 1) concept change or focus shift in all team members and hospitals/clinics from physician-led healthcare service to truly engaged partnership with patients and their families, and 2) organizational and policy change to reflect patient centered care principles. All of these changes will have a big impact on everyone, in every aspect. PFCC will require more time to get patients and families involved, which translates to more work for health care providers and “loss of control” by the physician in some way (Pollack& Koch, 2008 & Stewart et al, 2000).

In my opinion, there are two levels of PFCC: 1<sup>st</sup> level of PFCC is to engage patients and their families to be active members of the “team” so that together with the healthcare providers, they are making a complete care plan, making decisions, willingly being recipient of all the treatments, and working actively with all other team members for the recovery. At this level, the changes are mostly at the process. But the 2<sup>nd</sup> level of PFCC is to have a new organizational structure which includes active patient and family representatives. At Dana Farbar Cancer Institute (DFCI) (2013), there are two Patient and Family Advisory Councils (PFAC), one for adult patient, the other is for pediatric patients. The

PFAC are designed to “provide ongoing input on patient care, program planning, and organizational priorities and decision-making” (Reid Ponte, 2003). With organizational structure and system change, true change can occur – shift from physician centered care to patient centered care.

### **Approaches for implementing a model of patient and family centered care in the practice setting**

Weigand et al ( 2013) described how they applied PFCC for end of life care in the US. A few key points worth mentioning here are: PFCC is essential to high-quality care for end of life patients; it is important that families receive direct, honest information from consistent health care providers; a shared decision-making model is fundamental in which families and health care providers make decisions together based on the patient’s wishes. When we care for the end of life patients in our palliative care unit, we (health care providers) normally will call a meeting with the patient’s family. At the family meeting, we will tell the truth about the diagnoses, discuss treatment plans and options with the family as soon as we know that the patient is “at end” state. Most of patient families do not want the physicians or nurses to discuss the details of very poor prognosis with the patients directly (Weigand et al, 2013).

The reason for the families to withhold the information to the patients is that they do not want to burden the patient and increase the patient’s concern, fear, and anxiety. Also, they want to ensure that hope will not be taken away, so that the patients still have the will to fight. We will inform the family that it is our (physician and nurse’s) duty to tell honest information to patients, if the family does not want the patient to know, we will invite a psychologist to discuss the pros-and-cons of withholding information and how to communicate with patients in this situation. If the family still wants to withhold the truth to the patient, an immediate family member has to sign a document to claim responsibility for the decision. Not telling the truth causes moral distress for many of the health care providers who believes they are being asked to lie to the patients, an action which they consider to be unacceptable and unethical ( Starzomsk, 2009).

In Thailand, health care providers have been practicing PFCC for more than ten years now. One example of implementing a model of PFCC

is our practice in the palliative care setting. In Thailand, there are many different cultures in different parts of the country. Most of Thai people are Buddhists. They believe that the soul of a deceased will stay at the place where he/she died because the soul does not know how to go back home and how to go to heaven. In the palliative care unit, they implemented a PFCC model. Most of “late stage” or “end of life” patients will tell their doctors or nurses that when they are near death or almost dying to not help them and to leave them to die peacefully, to not do anything to make their body hurt. Most importantly, they want to die in their own home so that their soul will stay there and not get lost (Krongyuth et al, 2014).

In Thailand, Family meetings with the patient’s family is a very important part of our PFCC practice. And we try to involve patients as much as possible since any treatment or extent of their life has to be done by coordination with the patients. We listen to the patients very carefully, especially by the bedside nurses. Most patients have the following wishes:

1) they want to die peacefully if they know their illness cannot be cured anymore, they do not want medical help when they almost stop breathing because they don’t want their body getting hurt. They believe that in the next life they will have a good body.

2) They want to offer food to Buddhist monks (whom were invited by hospitals to visit and comfort in the hospital) and to do merit every day until they die. They believe that this “doing good” behavior can make the patient go to heaven. 3) Before they stop breathing, they want their family to take them back to their home because they believe that it makes their soul stay at home so that it will not get lost. Based on the PFCC principle, we decided to honor all of those requests because we think that it will not affect the treatment plan and the hospital. We think that the PFCC is important in taking care of the patient at the end of their lives as well as for other patients with acute or chronic illness.

However, PFCC in the Philippines is the complete opposite of that in Thailand. It is affected by socio-economic factors. Usually, the end-of-life patient of poor families opts to stay at home and will only be taken to the hospital if they are about to die in hopes that they can be revived. One reason for this is hospitals require a large amount of money as a “deposit” in order to

for the patient be admitted. Because of the lack of a universal health care system in the Philippines, poor families tend to self-medicate their sick family members and only decide to take them to the hospital when signs and symptoms are exacerbated. Thanks to a new legislation that penalizes hospitals for not accepting emergency patients without a “deposit”, the number of these patients are expected to rise.

Nonetheless, patients who are not considered emergency cases and who are under palliative care are still inclined to stay at home and wait until their last breath. These patients are not given a choice per se, they actually decide to just stay at home to lessen the financial burden to their families. Instead of spending their hard earned money on their hospitalization, they would rather die in their homes without medical attention so that they can leave some money behind for their loved ones.

The choices that patients and families are given more often depends on their monetary capabilities. Usually, when a poor patient comes in to the hospital, the doctor will ask if they can afford the medical bills, if not then they have to move to another hospital. This practice of rejecting patients when they are about to die can be seen nationwide. Hospital administrators would direct their doctors to send these dying patients to other hospitals to avoid a loss of reputation and to defer the hospital’s morbidity rates.

Often times, doctors can be seen scolding patients and families since they are being persistent for the hospital to accept their dying patients. This results to patients and families suffering more and being stressed out. It adds on to the sorrow and guilt of the family members since they cannot do anything about the situation. However, if the patient has the financial means then the health care workers include the patient and their families in health care decisions. Although, proper PFCC is practiced in well-known and expensive private hospitals, majority of public hospitals are notorious to not practice this.

### **How to measure whether or not such a model would improve care processes and patient outcomes**

In Thailand, they have a clinical practice guideline (CPG) of using a model of PFCC for

end of life patients. They built a team including the physician, the nurses, and the psychologist to work together. The way they measure effectiveness of the model is by using a questionnaire to survey. After each patient passes away, they send a survey form to the family (and to the health care team) to ask the family of the quality of the care provided by hospitals and if they are satisfied with their service. The last part of survey is to ask for suggestion from team and patient's families. For the first 2 parts, they use a numerical scale system which forms our data. For example, satisfaction rated by families in 5 levels: 5 being extremely satisfied, 4 being very satisfied, 3 being satisfied, 2 being somewhat satisfied, 1 being not satisfied. The last part is summarized and submitted to hospital leadership team for review.

Every six months, the health care provider team conducts a meeting to review the process and to analyze the survey data since we want to improve the quality of clinical practice guidelines for the PFCC model in the palliative care unit. One measure we took after the review meeting is that we decided to create a prayer room in each ward in the hospital for Buddhist patients because we received suggestions from the patients and their families that the end of life patients wanted to pray every day. They believe that doing the prayer everyday will help the patients to be peaceful and will help reduce the stress of the patients and their families as well, because their families have to take the patient to the prayer room and do prayer together with the patient. In the prayer room, we provided the video of religion and Buddha. And we also have "the peace of mind" Buddha temple music playing to help the patient relax. As a result, the survey showed that the satisfaction level of the patients and their families increased for almost 30% in the last 5 years.

Even though they have started PFCC practice in our hospital for ten years, we are still at the initial phase since complete PFCC implementation requires change of organization and leadership structure to get patients and families involved in the planning, program development and other aspects of the patient

care, like DFCI did in late 1990s (Reid Ponte, 2003).

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