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Research Article

Understanding the Practice of Collusion on End of Life Care in Singapore

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Abstract

The practice of collusion is commonplace within Asian healthcare settings. Here we study a typical case of collusion within the Singapore setting to highlight the rationale and the predisposing factors behind this practice. Through such understanding, it is believed that a better means of practice is possible- ostensibly through the use of a multidisciplinary team approach to ensure that the best interests and goals of the patient are protected.

Keywords: Collusion, end of life, Singapore, familialism, Confucian.

Introduction

The moderation or even the omission of information pertaining to a life threatening diagnosis is a common occurrence in Singaporean clinical practice (Tan et al 1993, Low et al 2000, Krishna 2011a, Krishna 2011b, Phua et al 2011, Tan et al 2011, Toh 2011, Foo et al 2012). A patient's relatives will often act unilaterally and without the patient's knowledge to restrict the patient from learning about his or her diagnosis, and the medical and nursing teams may facilitate this deceptive collusion (Krishna 2011a, Krishna 2011b). Indeed, it is not uncommon that some families insist that hospice home care nurses do not wear their hospice uniforms when attending to their loved one, so the patient does not suspect they are receiving palliative care. Some families enter the cancer center by the back door, so the patient does not see the word ‘cancer’ on the sign at the centre entrance.

However, the patient’s family is usually motivated to act this way because they wish to protect their loved ones from hurt and disappointment, to preserve their hope and to maintain their filial obligations to care for their family members which are rooted in social and local cultural beliefs (Goh 2007, Goh 2008, Ho et al 2010, Krishna 2011a and Krishna 2011b). Collusion arguably stems from prevailing Confucian ideals, but this practice has been at odds with both the patient’s wishes and the law (Mental Capacity Act Singapore Cap 4A, 177A). In fact, the Singapore Mental Capacity Act and the Advance Medical Directive Act promote autonomy and decision-making in the patient’s best interests (Mental Capacity Act Singapore Cap 4A, 177A). We will use this case study to analyze the impact of collusion on the consent and decision-making process, and explore the tension between the legal requirements and actual practice.

Case Description

LFK was a 78-year-old male with preexisting heart and lung diseases when he was diagnosed with advanced lung cancer, which had metastasized to multiple organs including his liver, lungs and brain.

LFK's relatives informed the doctors that he should not be told he had cancer because they feared he would be distressed, lose hope and the will to live. *They insisted that LFK only be told he had a "stubborn but treatable chest infection" caused by his lung* *problems. The relatives also argued that LFK probably lacked capacity to make his own decisions, and even if he could he would prefer his eldest son to make all the decisions on his behalf.*

Given the complexities of LFK's medical condition, gauging his capacity was a difficult task not least because his steroid induced diabetes that caused confusion and drowsiness. Although LFK experienced brief interludes of lucidity, his relatives made all the care and treatment decisions without ever involving him in the deliberative process. As a result the healthcare professionals enlisted the relatives to determine care decisions, and they also ultimately decided upon a course of treatment.

Over a period of six months the doctors treated him unsuccessfully with three different lines of chemotherapy. LFK's disease continued *to progress and it was not long before his condition worsened further. Comfort measures were introduced without LFK ever being involved in the deliberative process. Indeed LFK remained ignorant of his condition despite brief periods of lucidity till he died one month later.*

Comment

Prevalence of Collusion

Collusion is incompatible with Singapore law and modern medical standards, but its prevalence within regnant medical practice is engrained. Local studies appear to confirm the practice of collusion and its unchanging nature over a 30-year period (Tan et al 1993, Low et al 2000, Krishna 2011a, Krishna

2011b, Phua et al 2011, Tan et al 2011, Toh 2011, Foo et al 2012). A local study conducted in 1993 of a small sample (n=94) comprising of specialists, and general practitioners revealed that 90.4% would tell the family the diagnosis, 84% will accede to the family's request not to disclose the diagnosis to the patient and 23.4% would accede to the family's request not to tell the patient the diagnosis even if the patient insists on knowing it (Tan et al 1993). A later study in 2004 on patients, referred to the hospital's palliative care service, found that 70% of patients were unaware of their diagnosis at time of referral, and 54% wanted to know if their illness was life threatening (Low et al 2009).

Worryingly, two studies carried out at a local hospital in Singapore revealed that whilst 78.8% of physicians claim that they would involve the patient in the end of life decisions, only about 9.2% of terminally ill patients were involved in Do Not Resuscitate decisions (Foo et al 2012, Yang et al 2012, Ching et al 2013).

These findings highlight the primacy of the family in the deliberative process, and raise questions as to the root of their elevated positioning within the decision making process.

The Role of the Family

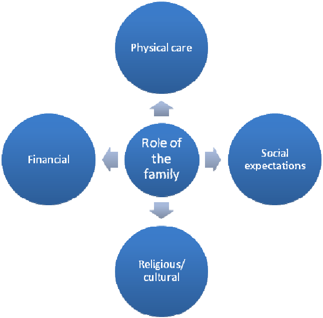

Fig. 1: Factors that Influence the Position of the Family within the Decision Making Process in Singapore

The influence of the family may be considered as arising from four elements (Fig1). These divisions are entirely arbitrary with a significant overlap presented amongst the four elements. The family's involvement in the healthcare decision-making process can probably be attributed to the Confucian ethical and social model practiced by the majority Chinese population in Singapore. (Goh 2007, Goh 2008, Ho et al 2010, Krishna 2011a, Krishna 2011b). Interestingly, these same elements are also seen within all the other major races (Malays and Indians) presented in Singapore, and may be described as "Asian Values" within the Singaporean context (Goh 2007, Goh 2008, Ho et al 2010, Krishna 2011a and Krishna 2011b).

Conceptually, this framework perceives the individual as having a dual identity - a horizontal or familial identity, and an autonomous individual or vertical identity. (Ho et al 2010). It is this horizontal or familial identity that lends support for ‘close’ familial involvement within the deliberative process (Ho et al 2010). However, this framework that would appear within modern Singaporean culture to be aimed at protecting the best interests of the patient has been variously construed (Krishna 2010, Krishna 2011a, Krishna 2011b, Krishna 2011c, Krishna and Chin 2011, Krishna 2012). . Societal expectations dictate that the relatives act as the patient’s primary caregivers, and they must maintain hope and never give up on the patient.(Krishna 2010, Krishna 2011a, Krishna 2011b, Krishna 2011c, Krishna and Chin 2011, Krishna 2012). As a result, families frequently collude with physicians and nursing teams, and decisions are taken so that, everything is done to save the patient.

Failure to meet these expectations can result in disapproval of the community as a whole (Ho et al 2010, Krishna 2011a, Krishna 2011b). Ho et al have previously described this local societal pressure as "losing face" which would suggest that one's "personal honor and dignity judged by his or her community" would be jeopardized (Ho et al 2010). Such an outcome is "fearfully avoided" thus compelling the family to remain involved in the decision-making process and care provisions (Ho et al 2010).

Thus, families attempt to maintain hope and spare their loved ones 'unnecessary' anguish of a poor or cancer prognosis (Goh 2007, Goh 2008, Ho et al 2010, Krishna 2011a, Krishna 2011b). Consequently, families frequently collude with physicians and nursing teams to either circumnavigate the patient's involvement within the deliberative process by not providing them with the relevant information or moderating the information provided to patients. The end result is the practice scene we now witness in Singapore.

On the other extreme, some families place their collective interest above those of the patient (Krishna 2011a, Krishna 2011b). Although, it would appear as though the patient's interests are protected within the collective family interest, all too often this does not follow in practice (Krishna 2011a, Krishna 2011b).

Here particularly, when the interests of the family are at odds with the interests of the individual patient, it is the former that takes precedence (Krishna 2011a, Krishna 2011b, Krishna 2012).

Familial self-serving interests are not altogether unsurprising, given that in Singapore 66.7% of elderly persons (aged 65 and above) live with their children, and 62.8% rely on an allowance from their children as their main source of financial support (Statistics Singapore Newsletter 2012). The introduction of the Maintenance of Parents Act merely compels children to provide for the basic needs of their parents, and therefore its effects on healthcare decision-making have been limited (Krishna 2012, Maintenance of Parents Act, Cap. 167B, 1996 Rev Ed Singapore). The patient's relatives would argue that, as they either live with the patient or provide financial assistance to them, they should have the right to be involved in the patient's healthcare decisions, because those decisions have a direct impact on them whether financially or in relation to their family dynamic (Krishna 2012).

Worryingly, local physicians and nursing staff also appear to prioritize the opinions of the family even when the patient is competent. Indeed, a recent local study revealed that local physicians would likely overturn the wishes of a previously competent patient, in favour of opposing familial views should the patient become unconscious (Foo et al 2012). Thus, it is not at all surprising that within prevailing Singaporean practice to see health care, professionals speak to the elderly patient's relatives first when discussing the patient's condition (Goh 2007, Goh 2008). Arguably, competent elderly patients are infantilized if they are treated in this way, and denied the right to express their healthcare preferences (Krishna 2011a, Krishna 2011b).

Legal Impact of Collusion in Singapore

The framework of the Mental Capacity Act allows families to be involved in the patient's healthcare journey, but the competent patient should dictate the extent of that involvement. That right would extend to the patient informing the doctor whether they would like to know their diagnosis, and who should make treatment decisions. If the patient would prefer that a relative or the doctor make treatment decisions for him or her, then that request should be respected. There have been no reported legal cases in Singapore regarding the legality of treatment provided to a competent patient, who has assigned another person to make those decisions on his or her behalf.

Healthcare professionals are placed in a difficult position because they know that competent patients should be informed of the diagnosis, and make treatment decisions unless there is a therapeutic reason for withholding this information. Here, the relatives intervened at the outset, and were adamant that LFK should not be told of the situation. Should healthcare professionals object and counsel relatives on the reasons why the patient should be told? Yes, they should but what if that does not work? What if relatives threaten to make a complaint? This pressure on the healthcare professional can be quite overwhelming, and situations like this are difficult to manage in a busy healthcare institution (Chan and Goh 2000). The support from administrators on handling these situations, and mandating the adoption of best practices that are aligned with the relevant legal principles would be helpful in eradicating collusion (Low et al 2009). Although collusion may be entrenched in our communities especially for elderly patients at the end of life a concerted institution-wide measure to eradicate it through educating patients their families and healthcare professionals should work (Low et al 2009).

By cooperating in the collusion, healthcare professionals place themselves at great risk of breaching their professions' Code of Ethics and the law (Duties of a Doctor General Medical Council 2006, Duties of a Doctor Singapore Medical Council 2009). LFK was treated with three lines of chemotherapy. He did not know he had cancer, so he could not have given his consent to chemotherapy treatment. The doctors would have been acting on the family's treatment preferences, but relatives have no legal authority to consent to treatment on LFK's behalf. (Re T 1992, Re

LP 2006). Therefore, under the law, the doctor committed battery by treating LFK without his consent (Chatterton v Gerson 1981). Furthermore, by sharing LFK's diagnosis and other healthcare information with his relatives, the doctors have breached their duty of confidentiality to LFK. (Duties of a Doctor General Medical Council 2006, Duties of a Doctor Singapore Medical Council 2009).

If collusion was not present, the best practice would be to conduct a mental capacity assessment to ascertain whether LKF could make his own treatment decisions. Even though, the family contended that LFK might lack capacity to make his own decisions, this did not mean that he actually did. The two-stage capacity test mandated in the Singapore Mental Capacity Act first requires that the person is suffering from an impairment or disturbance that affects the function of the brain or mind, and second, that impairment or disturbance causes the person's inability to make a decision at a particular time (Mental Capacity Act, Cap 177A, 2010 Rev Ed Singapore (section 4(1)). The first stage of the capacity test was met given LFK's medical condition. The second part of that test is amplified into four strands, so that a person is unable to make a decision if he or she is unable to (a) understand the information, (b) retain the information, (c) use or weigh the information, or (d) communicate the decision (Mental Capacity Act, Cap 177A, 2010 Rev Ed Singapore (section 5). Here, there was a question over LFK's capacity to make serious treatment decisions because the cancer had spread to the brain. To settle any doubts over his ability to make treatment decisions, the healthcare professionals should act prudently and assess his capacity. However, all these steps were avoided because the collusion denied LFK autonomy.

Conclusion

LFK's case highlights the growing unease amongst many practitioners within family centric societies such as Singapore, when addressing the issue of information provision. Whilst focus of this paper has been upon the Singaporean context, there is a growing awareness that the patient centered care is compromised, and respect for the person circumnavigated by the practice of collusion in many Asian nations, as well as certain communities in the Americas, Africa and Europe (Laxmi and Khan 2013, de Graaff et al 2012, Vivian 2006, Qiu 1987, Tsai 1999, Cheng et al 2012, Chan and Goh 2000, Chan 2006, Cheng et al 2012, Hui 2008). The implications on clinical research too become a concern in the face of possible coercion by the family for patients to participate in clinical trials. Patients may in fact be participating in clinical trials without undergoing the appropriate consent process.

Reducing the incidence of collusion is challenging. Patient and healthcare professional education on the pitfalls of collusion may be helpful. The solution to this issue may lie in a two-pronged approach – an intensive education of health care professionals; and the general public on the issues pertaining to collusion and the employ of a multidisciplinary team (MDT) decision-making process may provide a solution in tandem with. Medical ethics is taught in the Singapore medical schools and in the subsequent medical specialty training. Physicians and other healthcare professionals are also receiving additional training on how to better address the issues underlying collusion, and how to better broach difficult issues with patients and families in a sensitive and professional manner.

In the meantime Low, et al have also suggested a sustained education program to increase awareness of patient rights and the problems with collusion amongst the general public with some success (Low et al 2009). Further efforts sponsored by governmental services and using multimedia to help disseminate information into the ills of collusion, how best to address it and the promotion of patient's rights are the key. Patients and families need to be assured that physicians have been adequately trained to break bad news in a sensitive and respectful manner.

Here the decision making process follows a multidimensional review of the patient's case that would involve the family. The final decision with regards to the amount of information that ought to be provided to the patient; and the best means of protecting their interests following of due consideration of the psychosocial, emotional, cultural and practical considerations in addition to the clinical concerns, are left in the hands of the multidisciplinary team who are obliged to protect the patient's welfare. Under such an overarching welfare based model, LFK's condition and interests would be better supported.

Conflicts of Interest: None

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