Reducing Collusion Between Family Members and Clinicians of Patients Referred to the Palliative Care Team

Abstract

Objective: Collusion refers to a secret agreement made between clinicians and family members to hide the diagnosis of a serious or life-threatening illness from the patient. Our goal was to reduce the rate of collusion among the family members of patients referred to our institution’s palliative care service such that 80% of patients would be aware of their diagnosis within four weeks of referral to the service. We aimed to achieve this target within six months of starting the project.

Methods: We undertook a clinical practice improvement project using the methodology of Brent James et al of Intermountain Health to see how we could reduce collusion among clinicians and family members of patients with advanced-stage cancers. This strategy included creating awareness among patients, family, and clinicians of the problems with collusion from the standpoint of each group; adopting an empathetic and compassionate approach to communication; using pamphlets; seeking patients’ views; empowering families to reveal the truth to patients; and supporting patients and families until the last moment of each patient’s life.

Results: Between December 2004 and June 2008, 655 patients with advanced-stage cancers were referred to us. We were able to maintain an average awareness rate of nearly 80% of patients starting in February 2005, when we implemented awareness measures.

Conclusion: The deeply entrenched cultural practice of collusion can be changed with simple strategies based on the universal principles of medical ethics and best practices.

Table 1. Reasons families choose to keep a diagnosis from a patient

<table>
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<tr>
<th>Reason</th>
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<tbody>
<tr>
<td>Disclosure causes the patient to lose hope</td>
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<td>Disclosure leads to depression</td>
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<tr>
<td>Disclosure hastens the progression of the illness and death</td>
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<tr>
<td>Disclosure increases the risk of patient suicide</td>
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<tr>
<td>Disclosure may cause psychologic pain for the patient</td>
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<td>Family members themselves may not be aware of the nature and severity of the illness</td>
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<tr>
<td>Family members may be in denial</td>
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<td>Family members may be in conflict</td>
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Introduction

Collusion, in the medical context, occurs at the family’s request and is the default practice in many Asian cultures. It is contributed to, in no small part, both by the widespread practice of physicians disclosing a diagnosis to a patient’s family members before revealing it to the patient and by clinicians’ underestimation of the information needs of patients. Clinicians may also regard collusion as an easier option than telling the truth because it reduces their own stress and anxiety.
Numerous Asian and European studies have shown that up to 60% of cancer patients may not be aware of their diagnoses, although more than 90%, if given the choice, would choose to be told the truth. A preliminary survey conducted at our hospital in Singapore in 2004 revealed the following characteristics of patients referred to our palliative care service:

- Unaware of their diagnosis at time of referral: about 70%
- Would like to know about their illness: 67%

Table 2. Why collusion goes against the principles of best clinical practices

<table>
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<tr>
<th>Patient factors</th>
<th>Clinician factors</th>
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<tr>
<td>Collusion is antithetical to patient autonomy and to the right to self-determination</td>
<td>Collusion results in a breakdown of the clinician–patient relationship and a loss of trust between patients and clinicians</td>
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<tr>
<td>Revealing the diagnosis to relatives before revealing it to patients breaches patients’ right to medical confidentiality</td>
<td>Clinicians may face treatment noncompliance from patients and may be unable to provide optimal treatment, such as radiotherapy and chemotherapy</td>
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<tr>
<td>Patients are unable to give informed consent if they are not aware of the underlying illness and thus may not obtain appropriate or optimum and timely treatment</td>
<td>Patient wants patient to know diagnosis.</td>
</tr>
<tr>
<td>Patients may not be able to complete unfinished business and tasks prior to their deaths</td>
<td>Patient wants clinician to break bad news.</td>
</tr>
<tr>
<td>Patients who sense something amiss may come to distrust their relatives and clinicians</td>
<td>Family wants clinician to break bad news.</td>
</tr>
<tr>
<td>Many patients suspect the diagnosis anyway, given their symptoms and physical deterioration</td>
<td>Family wants to break bad news themselves.</td>
</tr>
</tbody>
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Family factors

- Family members will have to bear the burden of being untruthful or even deceptive to their loved ones, which may lead to guilt later
- A barrier to communication is erected as family members become avoidant at a time when they are most needed by patients
- Families will have no guidance in making treatment decisions, especially closer to the end of life

Clinic factors

- Collusion results in a breakdown of the clinician–patient relationship and a loss of trust between patients and clinicians
- Clinicians may face treatment noncompliance from patients and may be unable to provide optimal treatment, such as radiotherapy and chemotherapy

Figure 1. The root causes of collusion.
such that 80% of them would be aware of their diagnosis within four weeks of referral to the service. We aimed to achieve this target within six months of starting the project.

Methods
Defining the Problem

This project was carried out in Alexandra Hospital, a 400-bed district general hospital located in Singapore. Its main specialties are general medicine, geriatric medicine, orthopedic surgery, and general surgery. The palliative care service sees about 300 patients a year.

To begin tackling the problem of collusion within the palliative care service, we created a flow chart detailing the stream of information from the time that a diagnosis of a terminal or life-threatening illness is confirmed to the time at which a patient is fully aware of the diagnosis. We found some important factors that led to collusion (Figure 1). It was evident to us that families and attending physicians were the two most common groups of “factors” leading to the high incidence of collusion in the inpatient setting, with the former being more important than the latter. Hence, we looked in greater detail at the possible reasons families may choose collusion over telling the truth and developed a Pareto chart (Figure 2). As we studied the reasons in greater depth, we realized that the overarching theme of almost every way in which collusion was perpetuated had to do with communication or the lack of it. Hence, we devised a strategy to tackle it from a mostly communicational standpoint.

Strategies for Intervention

The first step was to create awareness that collusion was indeed a huge problem among the terminally ill and why, in most instances, it was detrimental to the care of these patients and went against the most basic ethical principles of modern medicine. We then went on to adopt a multipronged approach to tackle this problem (Table 3) and devised an algorithm (Figure 3) to manage collusion.

The key points in the strategy adopted were:
- Acknowledging the problem, making the primary teams aware that collusion was generally inappropriate for patients and their families and should be addressed as soon as possible. We appointed a champion in each of the four main departments to promote awareness of collusion.
- Making family members aware of the gravity of the advanced stage

![Figure 2. Families’ reasons for choosing collusion.](image-url)

![Table 3. Multipronged strategy to tackle collusion in the inpatient setting](table-url)
Reducing Collusion Between Family Members and Clinicians of Patients Referred to the Palliative Care Team

Figures 3 and 4 show the proportion of patients who were aware of the diagnosis, from December 2004 through June 2008. The measures were implemented during a one-month period in February 2005. With the exception of December 2005, when the number of referrals was at its lowest, we were able to maintain an average awareness rate of nearly 80% as a result of our interventions. The rate was sustainable for a period of more than three years. The awareness rate was arrived at by dividing the number of patients who were aware of the diagnosis within four weeks of referral to the palliative care service by the total number of referrals for the whole month. The numerator excluded those whose families adamantly refused to have the diagnosis revealed to the patient and those who had severe cognitive impairment, which made it impossible for them to grasp the significance of their illness. During the project, 655 were referred to the palliative care service.

Discussion

Telling the truth about serious or terminal illnesses is not a common practice in many Asian cultures. Among the Chinese, who form the majority ethnic group in Singapore and among whom the Confucian tradition is prevalent, physicians tend to approach family members first with the bad news, leaving up to family members the decision of whether to disclose the diagnosis to the patient. Families who tend to be paternalistic and overprotective usually choose collusion over disclosure. This stance, albeit misguided, is born of love and concern for the patient. These families usually have pure intentions.

This project was not so much about trying to break collusion at all costs but more about giving patients a voice. It was about respecting patient autonomy and trying to align families’ decisions with those of patients. We concede, however, that there can be instances when the risk of telling the truth outweighs the benefit and in certain circumstances can even hurt the patient. These rare situations are usually manifested by the family’s strong insistence on keeping the truth from the patient. We respect families’
Reducing Collusion Between Family Members and Clinicians of Patients Referred to the Palliative Care Team

wisdom too, as family members are the ones closest to the patient and hence know the patient best.

Conclusion

We have learned that collusion, despite being deeply entrenched in clinical practice in our part of the world, can be reduced with our strategies. These strategies are based on creating awareness, enabling patients to exercise their autonomy, educating family members, communicating empathetically and compassionately, and empowering family members to communicate about the difficult issues of serious illness and death. We have incorporated most of those strategies into our standard assessment of all palliative care patients. We routinely assess patients and their family members for collusion and use those strategies to manage it. Our goal was also to spread the principles espoused by this project to other departments and other hospitals within our health cluster. We achieved the latter by making numerous presentations to senior management committees and in such settings as clinical forums and team meetings.

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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References