Malaysian Family Physician 2006; Volume 1, Number 2&3

Online version: http://www.ejournal.afpm.org.my/

Case Reports

COLLUSION IN PALLIATIVE CARE

Khoo Siew Beng *FRACGP*
Penang Medical College.

Address for correspondence: Dr Khoo Siew Beng, Department of Family Medicine, Penang Medical College, No 4, Sepoy Lines Road, Penang 10450, Malaysia. Tel: 604-2263451, Fax: 604-2284285, E-mail: sbkhoo@pmc.edu.my

ABSTRACT

Collusion is generally an act of love and protection for a close relative from knowing the bad news with regard to diagnosis and prognosis of his/her illness. Evidence from research studies showed that although truth hurts, deceit may well hurt more. Filial duties and obligations form the basis for non disclosure in some cultures while principles of informed consent and patient autonomy are ethical and legal obligations to provide patients with as much information as possible in some countries. Collusion serves to isolate the patient, cause family disruption, incurs tremendous psychosocial stress on patient and relatives and leads to poor standard of healthcare. It is vital to assess for presence of collusion from the outset and to avoid this distressing dilemma. This case report is an example of the great cost of collusion on the carer's part.
Keywords: Collusion, anxiety depression, guilt, ethical issues, cultural acceptance, truth telling.
Khoo SB. Collusion in palliative care. Malaysian Family Physician. 2006;1(2&3):62-64

CLINICAL SCENARIO

Miss A, a 22-year old teacher, suffered from severe palpitation, tremor and intense feeling of fear whenever she went to work. Her symptoms had become progressively worse over a period of 10 months. She was diagnosed with anxiety depression with suicidal tendency and was under the care of a hospital psychiatrist for 2 months when I met her. She was treated with alprazolam for panic attacks and a course of sertraline for her depression. She attributed her illness to stress at the new working place.

Casual conversation with Miss A and her aunt revealed that Miss A's father was diagnosed with gastric carcinoma a year earlier. Partial gastrectomy was done for him followed by oral chemotherapy. Lately it was discovered that he had metastases to the surrounding lymph nodes and had to undergo another surgical intervention.

The patient himself was told that he had some "toxic" tumour in the stomach that had been removed and that he would be fine. Miss A, being the eldest in the family, and her aunt who is a nurse were told of the diagnosis. All the other family members including Miss A's mother, brothers and sisters did not know about the malignancy. Miss A was adamant that her father must not be told of the truth for he would not be able to take it.

Miss A used to have an optimistic, cheerful demeanour, without any past history of anxiety depression. Her symptoms started soon after diagnosis of her father's cancer was revealed to her. At about the same time she was transferred to work in a new school. On assessment we could not identify any specific factors associated with her anxiety depression and panic attacks whenever she went to school. I realized that Miss A's anxiety depression was more likely due to the cost of collusion rather than stress at the working place.

Disadvantages of collusion were explained to both Miss A and her aunt. Miss A's aunt decided to reveal the truth to the whole family in spite of protest from Miss A. The patient was quite depressed the first few days. Given time and support from the family, he came to terms with the fact that he was dying. He discussed his plans with the family with regard to his will and other legal matters and his funeral arrangement. He prepared the family emotionally for his final departure. He had a good peaceful death in the end.

Miss A's symptoms improved soon after the truth of malignancy was disclosed to the patient and other family members. She realized that her father was able to cope better than she anticipated. There was better communication among all family members, everyone was free to express their emotions and had the opportunity to provide support for her father. After witnessing the favourable outcome from the disclosure of the truths, she expressed her gratitude and described her feeling as "a heavy burden taken off my shoulder." Miss A was eventually called off her psychiatric medication. She is still teaching at the same school and is now pursuing an off campus degree course in Science.

DISCUSSION

Do cancer patients want to know the truth?

"The news would kill him – you must not say anything". This is a commonly expressed belief that what people do not know does not harm them. 'No news is not good news,

it is an invitation to fear' Evidence from research studies showed that although truth hurts, deceit may well hurt more.[1]

In a recently published paper examining the information preferences of a heterogeneous sample of 2331 patients with cancer in UK 2027 (78%) wanted all possible information, be it good or bad news.[2] The evidence for substantial cultural differences regarding information needs among cancer patients is rather thin or inconclusive. For example Fielding and Hung challenged the notion that Asian patients with cancer and their families want less information than their western counterparts in a series of well conducted studies.[3] In some Chinese culture filial duties and obligations form the basis for non-disclosure.[4] In Japan it is a common practice for physicians to explain about the patient's condition to family members first and that the patients are informed only when their families agree. This is due to the Japanese culture that the group's wishes are more respected than those of the individual that indicates that the sense of belonging to the family is very strong.[5] In North America, principles of informed consent, patient autonomy, and case law have created clear ethical and legal obligations to provide patients with as much information as they desire about their illness and its treatment.[6]

Collusion is most often seen between patients and relatives but also between professionals. Collusion is generally an act of love or a need to protect another from pain. Colluders will often argue that they know the patient better than the health professionals do and know "what he can take". They may further argue that telling the truth may take away hopes.[7]

Disadvantages of collusion

Data indicated that awareness of diagnosis did not have a negative influence on emotion or global health status / quality of life. Withholding the truth and presenting a false reality could lead to a lack of cooperation with the doctor, prohibits the patient and carers from sorting out practical issues, denies them opportunities to reorganize and adapt their lives towards the attainment of more achievable goals, realistic hopes and aspirations.[1]

At this stage when the patient is in great need of psychosocial support, false reassurances given by the doctor and family members enforce a silence around the subject of diagnosis. Collusion may also result in a heightened state of guilt, fear, anxiety, confusion, depression and conflicts for both the patient and carers for it is not easy to try to keep a secret from someone living close together.[8] The above case report is an example of the great cost of collusion imposed on Miss A who was not aware that this was the cause of her anxiety depression.

Disadvantages of collusion were explained to both Miss A and her aunt. Miss A's aunt decided to reveal the truth to the whole family in spite of protest from Miss A. The patient was quite depressed the first few days. Given time and support from the family, he came to terms with the fact that he was dying. He discussed his plans with the family with regard to his will and other legal matters and his funeral arrangement. He prepared the family emotionally for his final departure. He had a good peaceful death in the end.

Steps in dealing with collusion[9]

It is essential to assess presence of collusion at the first consultation and try to discourage it. This is not to imply that health professionals must tell everything to everyone but rather assess how to give what the individual patient needs and what he or she can take.[10]

Prevention

It is vital to acknowledge from the outset that this distressing dilemma is almost always avoidable if patients are always consulted first about the diagnosis.

Interview the relatives to gain their trust.

- Acknowledge the presence of collusion.
- Acknowledge the difficulty of the situation for the relative and that he or she is closest to the patient.
- Assess the relative's understanding of the disease and its impact on the family.
- Review the reasons for not telling the patient; acknowledge some of these are good and come from the best of motives.
- Consider the consequences and potential harms of not telling.
- Focus on the personal cost to the relative of maintaining a deception.
- Ask what the relative thinks is the patient's level of understanding.
- Suggest that research evidence indicates that most patients would like to know the truth and that they are already aware that something serious is happening.

Seek permission to speak to the patient alone

Indicate that you have no intention of revealing the truth to the patient but only to assess how much he knows and how much he wants to know unless he asks a direct question when it will be inappropriate to lie to him.

Establish the patient's level of awareness

Seek permission to convey his awareness to his relative. Occasionally the relative is right and the patient gives clear signal he does not want to know. In this case it would be

infringement of their autonomy to force unwanted information upon them.

Open discussion with patient and family
Finally see the patient and the family together to share information, to offer support and follow up and to start setting realistic goals for the future.

CONCLUSION

There is no convincing evidence supporting the contention that terminally ill patients who have not been told of their situation die happily in blissful ignorance. A dying person witnesses their deteriorating body, fatigue and reduction in ability to function. The hollow cheerfulness and feigned optimism about unrealistic future goals, the anxious and stressed expressions on faces of people trying to maintain a lie are excruciating to witness.

REFERENCE

1. Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med.* 2002;16:297-303 [PubMed]
2. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centers. *Br J Cancer.* 2001;84:84-51 [PubMed]
3. Fielding RG, Hung J. Preferences for information and involvement in decisions during cancer care among a Hong Kong Chinese population. *Psycho-Oncology.* 1996;5:321-29 [Link]
4. Berger JT. Culture and ethnicity in clinical care. *Arch Intern Med.* 1998;158;2085-2090 [PubMed]
5. Uchitomi Y, Yamawaki S. Truth telling practice in cancer care in Japan. *Ann NY Acad Sci.* 1997;809:290-99 [PubMed]
6. Annas G. Informed consent, cancer and truth in prognosis. *N Engl J Med.* 1994;330:223-5 [PubMed]
7. Sykes J, Johnson R, Hanks GW. ABC of Palliative Care. Communication with patients, families and professionals. Edited by Fallon M and O'Neill B. BMJ books, 1998.
8. Khoo SB. Facts and fallacies in palliative care. *Asia Pacific Family Medicine.* 2003;2:143-7 [PDF]
9. Faull C, Barton R. Managing complications of cancer, chapter 12. In: Faull C, Carter Y, Woof R. Handbook of Palliative Care. Blackwell Science, 1998
10. Iconomou G, Viha A, Koutras A, *et al.* Information needs and awareness of diagnosis in patients with cancer receiving chemotherapy: a report from Greece. *Palliat Med.* 2002;16:315-21 [PubMed]

Palliative care and cultural competency: useful websites

Lickiss JN. Approaching death in multicultural Australia. *Med J Aust.* 2003; 179 (6 Suppl): S14-S16 [HTML] (Full text of this 16-part series is free, follow the previous link)

Searight HR, Gafford J. Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Physician.* 2005;71(3):515-22 [HTML]

al-Shahri MZ, al-Khenaizan A. Palliative care for Muslim patients. *J Support Oncol.* 2005;3(6):432-6 [PDF]

Editor's note: With our multicultural background, surely you have differing views and perspectives on "death and dying". Do share them with our readers!