

Denial in Cancer Patients

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Case Presentation

First Case: LKY M/42

The patient was diagnosed to have nasopharyngeal carcinoma with lymph node metastasis 2 years ago, but he refused any treatment. In February 2002, he was admitted for poor general condition. He had marked edema of both lower limbs, with lung and liver metastases. His younger brother revealed that patient strongly denied the diagnosis of cancer and had defaulted follow up since the initial diagnosis of cancer.

Impression: This is a case whereby denial inhibits action of importance.

Second Case: PCL M/59

The second patient was diagnosed to have multifocal hepatocellular carcinoma with gross ascites and possible portal vein involvement in July 2001. The daughter noticed that patient had multiple somatic symptoms including poor appetite, abdominal distension, nausea and dyspnoea; but the patient denied all. His daughter worried that the symptoms would not be controlled. Moreover, he would not be aware that death is near, and any discussion on this issue would not be possible.

Impression: In this case the family members view denial as problematic and feel the need to confront it.

Third Case: LYW M/85

The third gentleman had Hartman's operation performed for carcinoma of sigmoid colon in November 1998. He was diagnosed to have tumour recurrence in liver in October 2001. The patient insisted that the tumor had been removed and he believed that it would not recur. The son understood the prognosis but requested the palliative care team to accept his father's denial in order to maintain his hope.

Impression: Denial may maintain morale in a difficult situation.

Denial in Cancer Patients – Topic Review

Denying that it is really a cancer, and hope, despite all odds, that it will all be made well, or it will be discovered that it was a misdiagnosis - this sort of delusion has been observed to last for several years in some patients. Some others just accept "the death sentence" and die. Not all who die have given up. Not every dying person comes to terms with what is happening in a way that is clear to the outside observer. Can we say who is right, and who is wrong?

Thinking on denial has come full circle, from early psychoanalytic teaching that denial was a maladaptive and immature defense to be confronted¹, to later understanding that denial was an adaptive response to illness.² Currently, denial is more likely to be promoted, implicitly or explicitly, to avoid confronting the reality of life-threatening illness.³ Today, the challenge in palliative care is not so much the confrontation of denial, but rather the avoidance of collusion with its use. Adding urgency to this movement is the suggestion that denial may even be associated with prolonged survival, at least for some cancer patients.⁴ Thus, in current practice, there is significant public pressure on physicians, to maintain hope and avoid negativity regardless of the medical reality.

What is denial?

Denial is the patient's refusal to take on board the bad news. It is a complex concept that has different meanings in different contexts and serves a multitude of functions. When a person finds the challenges too overwhelming, denial may be the coping strategy that "works". Denial, in this situation, provides psychological protection.⁵ However, denial of the illness or of its severity for some patients can cause delayed diagnosis or compromised compliance with treatment.⁶ Furthermore, denial is used within an interpersonal context. Each person determines what information can be shared with others.³ Denial is not an all or nothing phenomenon.⁴ Most people use denial to one degree or another, denying some aspects of their illness at least some of the time. This denial may fluctuate widely on a day-to-day, or even a minute-to-minute basis. It is a dynamic process.

What are the outcomes of denial?

Outcome research on denial has produced mixed results. Overall, for patients with physical illness, denial may have some positive mood-regulating effects.⁴ However, results concerning the relationship between denial and medical outcomes have been conflicting and inconclusive. Some empirical studies suggest that denial may serve a useful purpose early on but may become maladaptive if sustained over prolonged periods of time.⁷ Other studies note the association between denial and diagnostic delays and treatment noncompliance.⁶

How do we manage denial?

1. It is important for all clinicians to understand their contribution to denial to ensure that the patient receives factual, clear information regarding the disease and its implication. We should make sure that the patient's denial is not due to lack of information, lack of understanding or lack of agreement with medical recommendations (Cousins, 1982; Shelp & Perl, 1985)^{8,9}
2. We have to assess denial carefully, including how and when it is used by the patient, the benefits and risks, the patient's usual coping style, the function it serves, and its significance for the patient and for others. Denial may be expressed in various ways, such as downward comparison, minimization of illness, or lack of emotional response. If these responses are present, it signals that the patient is frightened. Instead of confronting denial or challenging assumptions, it is best to provide support for patients to discuss issues concerned as they are able and at their own pace.¹⁰
3. Distinguish between a fact being denied (e.g. diagnosis of cancer) and implications of the fact denied (e.g. cancer will not return). The former may interfere with necessary treatment; the latter may maintain

morale in a difficult situation.¹⁰

4. It should be addressed directly when denial compromises patients' safety, such as not reporting symptoms, or not complying to treatment. When denial inhibits actions of importance, for example, making decisions on treatment, planning realistically, and communicating honestly with loved ones, it is also important to intervene.¹¹
5. We have to adopt a non-confrontational approach, with respect for the essentially protective nature of it. We have to explore and validate before attempting to change anything. Instead of judging the denial as "good" or "bad", it is more helpful to ask "Is this reaction helping the patient cope with his challenges?"¹² We must understand that it serves a healthy purpose in many instances, and we need to demonstrate that we are prepared to allow patients to have their own responses to their own life situations.
6. If denial is causing significant problems, direct confrontation may only increase the use of denial.¹⁰ For example, we should not tell a patient directly in this way: "It's the cancer ...it's killing you ...you should make use of your limited time to complete your family business and let your loved one say good-bye to you." In general, respect and support for the patient, including his defenses, yields far more therapeutic benefits than trying to change or override such defenses. Even when the defenses are extremely maladaptive, encouraging their positive aspects and building on them as strengths is more likely to be beneficial than direct confrontation and attack; such as encouraging a patient to use pain medications to increase independence and control over symptoms. In this way, the need for control is acknowledged, but the denial of the meaning of pain is not confronted directly. We can gently explore his or her understanding of the cause of his or her pain and weakness: "What is your understanding of the cause of this pain? What do you think is making you so weak? How can I best help you?"

A good policy for breaking bad news is to move slowly and let the patient determine the pace. At times, a more urgent discussion is required because of rapid clinical deterioration. When a more direct approach is indicated by clinical urgency, we must retain as much respect as possible for the patient's personal choices about coping, while expressing our concerns in as balanced and clear a way as possible: "I know you try to maintain as optimistic a view as possible about the cancer. I want to support your hopes about this. At the same time, I want to be sure that we have covered the decisions that need to be made if that is not how things turn out. We need to discuss ..."

7. Last but not least, emphasise to patients that they will not be abandoned. They will be supported and cared for, whether the medical news is good or bad.

Floor Discussion

Dr. K.S. Chan :

"I would like to reiterate the importance of distinguishing 'denial of the fact' and the 'denial of the implication of the fact', as illustrated in the three cases. The first gentleman basically denied the "fact" of the diagnosis of cancer by defaulting treatment and follow up; whereas the other two patients might know the diagnosis but denied the 'implications of the fact' that they were facing a disease being judged as incurable. For an ordinary people, the diagnosis is hard to deny as cancer is substantiated or confirmed by facts like histology, clinical picture, and other investigations. However when we refer to the 'implications of the diagnosis', the degree of 'truth' itself is basically subject to clinical judgement. For example, the survival as estimated by physician can be inaccurate. A patient who chooses not to accept the survival as predicted by the physician. The reason may be due to denial of death, or may be just a desire to seek alternative prediction.

Similarly, palliative care workers are tempted to label the advanced cancer patient as denial of death when one chooses to adopt a fighting spirit rather than choosing the letting go attitude. Modern psychology has given the powerful tool of identification of 'denial'. However, the labeling can be used rather loosely and inappropriately. After all, 'what is a truth' is not often as easy as we think."

Dr. D. Tse :

"I think the phenomenon is more than that of loose application of the term. Health care workers may tend to react or behave in such a way to reinforce the negativity of denial, or to lead the patient to behave as predicted by the initial labeling. For example, denial of the patient may invite blunt disclosure of the bad news by the frustrated professionals, which blocks communication further. Signing a refusal form certainly will not help the patient in accepting either. Patients may be perceived as non-cooperative if their denial lasts longer than a temporary phenomenon, as expected by most professionals. We feel frustrated when there is a gap between their responses and our expectations. However, our patients are facing a wider gap than us when facing the bad news. An element of acceptance is definitely needed in the non-confrontative approach in order for rapport to build up."

Dr. K.S. Chan :

"Is refusal of medical information by a competent patient ethically and legally justifiable? Though it is the duty for a doctor to provide relevant information, ethically we should not force a patient to accept the information that we disclose to them."

Dr. A. Thorsen :

"One of my patients illustrated this point very well. She was a middle-aged lady with a huge tumor in her abdomen, and she knew about the diagnosis. However, when being told that it was not resectable, she refused to believe in it and went back to mainland China to seek treatment, where the tumor was removed by operation. She remained well with no evidence of recurrence and she enjoyed a life of rather good quality."

Dr. K.H. Ng :

"I have another example here. Yesterday I was being consulted to see a patient who is just diagnosed to have incurable cancer. When I arrived at the ward, I found that the patient was missing. He obviously had chosen to run away from the ward right after he had heard the bad news. If he stayed, he might have no choice but to listen further to the implications. The patient may not be denying, but he may not be ready, or he is exerting his autonomy not to listen anymore."

Dr. M. Sham :

"I think it is important that doctors have the sensitivity to differentiate between them, and the sensitivity to pick up the clues that the patient is ready for more information or discussion. Such 'windows' may come along anytime during the caring process, and they give us opportunity to explore further on the issue of prognosis, or even death and dying. Meanwhile I do not think the presence of 'denial' should be a barrier to provision of palliative care to our patients."

Dr. K.S. Chan :

"During the caring process, the doctor often has to decide on how much and how best to disclose the information. Doctors have been criticised for hiding the bad news from patients in the past. Total disclosure is often promoted in breaking bad news. Recent studies revealed total disclosure without consideration may

not be the best approach. Conditional disclosure as guided by patient's own wish may be more appropriate."

Dr. D. Tse :

"Lastly I would like to add that patients who have adopted denial as a coping mechanism, be it adaptive, or non-adaptive, may put themselves in a rather lonely position. If we do not have the acceptance or empathy, we cannot be there with the patient, and we will not be in a position to help."

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