

Appendix 1

Dealing with Denial and Collusion

Denial

Denial is a basic primitive coping mechanism to protect us from information or events with which we cannot cope. By blotting out unpleasant facts it allows us to continue to function. Denial may be practised by the patient, by the family and/or by the professionals. Denial can be a very normal protective measure but in some situations it can be harmful and should then be challenged.

Professionals who feel that denial is unhealthy need to be sure that they are intervening in the best interest of the patient, not just because they feel the patient and family should fully accept the situation.

It should nevertheless be remembered that, in order to deal with their emotions, they usually need good symptom control alongside this.

Management

1. The first step in assessing denial must be to establish that the patient has been told the diagnosis in terms which he/she can understand. Is there written confirmation in the notes? What terms were used?
2. If the patient is in denial, decide if this is healthy or unhealthy. There are two main aspects to consider:
 - i. Is the denial reducing emotional distress?
 - ii. Is the denial affecting help-seeking behaviour and compliance?

If the patient is functioning well and denial is not prejudicing treatment, then it may be quite healthy. On the other hand, if denial acts as a barrier and prevents the patient from seeking treatment then it should be tackled. It is also appropriate to intervene in cases where the patient is in denial but is displaying a great deal of distress or pain that is not responding to treatment.

If the patient has dependents for whom provision must be made and planning is blocked by the patient's denial then this too is a situation where the denial should be challenged.

By gently exploring the patient's understanding and helping them to a more realistic view point it may help to resolve distressing symptoms/situations.

3. Denial can be difficult for professionals to work with, particularly when they prefer to communicate openly. However we must respect the needs of the patient and their ability to cope with the information at that particular time. Any attempts to modify denial should be for a specific reason, for example improving compliance with treatment, reducing emotional distress or planning care of dependants.

Phrases such as 'what if...?' and 'its sometimes best to plan for the worst and hope for the best' can help to open up the conversation, but it is unrealistic to expect all patients to come to terms with their mortality, indeed some are too ill and too close to death to open up the conversation.

4. Carers may deny the seriousness of the illness and expect too much of the patient. They need extra support to understand that life cannot continue as before.
5. Doctors and nurses may also deny the seriousness of a patient's condition and thus continue with or initiate inappropriate treatments. MDT working and cross-referral often help in the transition from curative to palliative treatment.

Collusion

Collusion occurs when the family conspire among themselves or with professionals to withhold information from, or lie to, the patient.

Collusion is a common problem particularly in the early stages of illness. We must remember that families are often well-intentioned and acting in what they believe to be the best interests of the patient. In trying to shield the patient, the family's actions are often of a protective and loving nature attempting to spare their loved ones from further pain and distress.

We should also respect the fact that the patient has the right to information about his/her diagnosis first. Has the patient given permission for you to disclose information about their diagnosis to their family? It is important to establish whether the family is trying to protect themselves or the patient.

Management

1. Listen to the family they know the patient better than you do and may have very valid concerns which should be explored. "What do you think s/he is expecting to hear?" "How has s/he coped with bad news in the past" Has anyone else in the family had cancer?" Having given them the opportunity to express their concerns, show that you empathise with their feelings and help them to understand that the patient has the right to the information. Do not rush this or the family can become quite antagonistic and this may be hard to reverse.
2. Reassure them that you will not walk in to the patient and impose information, but that if s/he asks questions you should answer them honestly but gently. 'If s/he is brave enough to ask, s/he deserves an honest answer'.
3. Explain to the relatives that if the patient asks a question we often answer it with a question in order to establish exactly what information the patient is seeking, e.g. "is it a cancer doctor?" If we reply "is that what you think the tests may show?" the patient may then go on to confirm their suspicion or may declare that they do not want all the details, or that they would like their spouse to be present.
4. The relatives are usually distressed and coming to terms with the bad news themselves, with a whole host of concerns and worries for the future. They have often not considered the consequences of their actions and not yet appreciated how difficult it can be to live with a lie and how isolated a patient will become, if the professionals and the family collude and pretend that all will be well. "How many years have you been married? This will be the biggest secret that you have ever tried to keep; they (the patient) may feel more and more lonely and not know who to trust".
5. Usually the family can be reassured that that no one is going to blurt out the bad news and that the issue will be handled sensitively. They may initially find talking openly to the patient, family and professionals can help to open up channels of communication.
6. Summarise your perspective:
 - > The rate and information given will be dictated by cues from the patient
 - > The patient's questions will be clarified and if they insist on a direct answer, this will be given honestly.