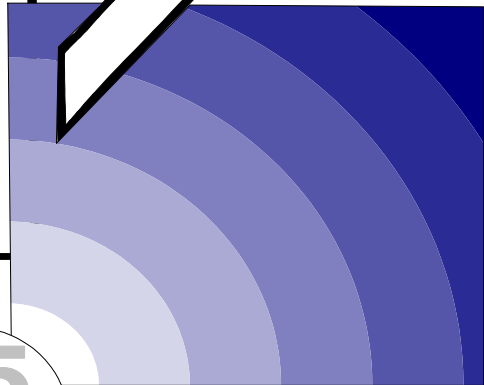
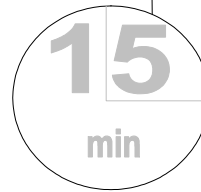


CLIP

15 minute Workshop



Psychological needs

8: Collusion and denial

Advanced level

Produced by
**Coleman Education
 Centre**
St. Oswald's Hospice
 Regent Avenue
 Gosforth
 Newcastle-upon-Tyne
 NE3 1EE

Tel: 0191 285 0063
 Fax: 0191 284 8004

This version written and edited
 by:
Paul McNamara
 Consultant in Palliative Medicine
 St. Oswald's Hospice, and
 Northumberland NHS Trust
Claud Regnard
 Consultant in Palliative Medicine
 St. Oswald's Hospice, Newcastle
 Hospitals NHS Trust and
 Northgate&Prudhoe NHS Trust

Aim of this worksheet

To develop some insight into collusion and denial by a patient, partner or relative.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor.
- Read the case study below, then work on the questions overleaf.
- The work page is on the right side, the information page is on the left.
- Work any way you want: you can try answering from your own knowledge (in which case fold over the information page), you can use the information page (this is not cheating- you learn as you find the information), or you can use other sources of information
- It should take you about 15 minutes. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know

Case study

John is a 46 year old man, married with two children who was diagnosed with motor neurone disease. He wanted to know the diagnosis and was told. He has been deteriorating rapidly this past week. Now back at home, you have been asked to visit by his wife Dora and daughter Angela.

When you arrive they explain that John doesn't know you have been called. You decide to see John for yourself, but at the bottom of the stairs, Dora grasps your arm & tells you John doesn't know he is dying & she & Angela have decided he should not be told. Dora thinks it best if you go outside & ring the doorbell, to make it look now as if you have just called in routinely to see John.

Getting started

Like much else in health care, it is important to keep an open mind. Don't assume that collusion and denial are bad or good- the issue is whether they are helpful or unhelpful to those involved.

Definitions

Collusion: this is something you do to another person, eg. a wife chooses not to tell her husband that he is seriously ill, or patients choose not to tell their family about their illness. It is 'denial-by proxy'.

Denial: this is something you do to yourself, eg. a patient refuses to accept the full reality of their illness. It is not the same as a gap in knowledge since you have to deny something! On the contrary, it is due to the individual struggling to cope with the knowledge they do have- it is an overload of reality.

Your reactions

When you first meet someone who is colluding in keeping information from their partner or relative, your reaction may be any of these:

- Surprise at the person's comments.
- Annoyance that someone is intervening between you and your patient
- Confusion as to what you should say now.
- A desire to join with the person and protect the patient.
- A determination that the patient should have the opportunity to decide for themselves.
- A wish to enable the patient and person to work this out together

The first step

1. F. Agreeing to their deception is collusion. It is not a promise you can keep without first talking to John.
2. F. This is going too far the other way- they may be right, after all!
3. F. Now you are getting cross about the collusion and colluding at the same time!
4. T. You need to start a dialogue with Dora and Angela to explore their feelings.
5. T. Denial is a good coping mechanism, as long as it is working for the individual.

The pros and cons of collusion and denial

The good things:

Collusion

Usually an act of love
 Provides a sense of protecting the patient
 Both person and patient may agree to collude!
 Superficially easier for carers
 Offers mutual protection

Denial

Allows information to be managed in stages
 Does not prevent consent for treatment
 Is a good coping mechanism

The down side:

Collusion

Occasionally it reflects control over the patient
 May isolate and patronise the patient
 May strain relationships because of 'secrets'
 May increase anxiety or depress mood
 Can create a 'conspiracy of silence' and distrust

Denial

Can prompt carers to push information
 Can prompt carers to insist on sharing information
 Can delay the sorting out of important business

The next step

What can you say that might help Dora & Angela? It can help to reflect the loving care that is being shown to John eg. "I can see that he has been hurt – you have all been hurt - by this devastating diagnosis and you do not want him to be hurt any more." Explain that you would be guided by John in the consultation, but if he asks outright then you would take it as an indication that he is ready to start discussing the diagnosis.

Telling or not telling: it is a professional's duty to find out how much the patient wants to know, not to decide whether the patient should know. See the CLiP worksheet on *Breaking Difficult News*.

Should you 'fudge it'? Sometimes a delay and a further visit clarify the situation for everyone and enables greater trust.

Summary points

Collusion is usually driven by love rather than control.

Collusion is usually estranging & isolating for all involved (professionals too!)

The purpose of tackling collusion is to enable closeness & honesty between those involved

The key to moving forward with partners and relatives is to fully acknowledge that they are behaving in the most loving way they know, but then to outline the down side. It can help to point out that although collusion may seem the most loving thing to do now, how will the "missed opportunities" be viewed looking back in bereavement ?

There are some situations when it is not helpful to challenge collusion eg if the patient is too ill to engage in the discussions needed or if the prognosis is too short to allow time for the discussions.

Reflect

- **Think about**
 -how you would feel ?
 -how you would react ?

Dora says you know nothing about her husband & she & Angela have talked long about what they are proposing & how to do otherwise would “destroy that dignified man up there”.

MCQ

- **What do you think of their plan?**

- | | | |
|---|------|-------|
| 1. Accept their plan & step outside to ring the door bell | True | False |
| 2. Tell them you're leaving as you feel you are here under false pretences | True | False |
| 3. Argue that you feel this arrangement is against your ethical principles but agree not to mention his deterioration | True | False |
| 4. Sit down with Dora & Angela to enquire why they feel this way | True | False |
| 5. Accept that denial is an acceptable way of coping | True | False |

Write

- **What are the pros & cons of their approach ?**

Good Things about collusion and denial	The Down side of collusion and denial
Collusion	Collusion
Denial	Denial

You arrive at an understanding that you will not initiate discussion about his deterioration. John has been lightly dozing, but sits up and asks how much time he has left.

Reflect

- **Think about how you should respond ?**

- What agreement would have to be agreed downstairs to enable a truthful reply?
- Is it your duty to tell the patient ?
- What are the consequences if you “fudge” it today? Do you have to sort it all out today ?

FURTHER ACTIVITY: Collusion and denial

Reflect on a time when you colluded with someone:
- what were your reasons for colluding?
-with hindsight, was it the best way?

FURTHER READING: Collusion and denial

Journal articles

Friedrichsen MJ. Strang PM. Carlsson ME. Breaking bad news in the transition from curative to palliative cancer care--patient's view of the doctor giving the information. *Supportive Care in Cancer*. 2000; **8**(6): 472-8.

Jenkins V. Fallowfield L. Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer*. 2001; **84**(1):48-51.

Lamont EB. Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine*. 2001; **134**(12): 1096-105.

McCague K. Collusion in doctor-patient communication. Doctors should adopt patient's perspective. *British Medical Journal*. 2001; **322**:1063.

Noone I. Crowe M. Pillay I. O'Keeffe ST. Telling the truth about cancer: views of elderly patients and their relatives. *Irish Medical Journal*. 2000; **93**(4):104-5.

Parker PA. Baile WF. de Moor C. Lenzi R. Kudelka AP. Cohen L. Breaking bad news about cancer: patients' preferences for communication. *Journal of Clinical Oncology*. 2001; **19**(7): 2049-56.

Rousseau P. Death denial. *Journal of Clinical Oncology*. 2000; **18**(23): 3998-9.

Truth in the most optimistic way. *Annals of Internal Medicine*. 2001; **134**(12): 1142-3.

Resource books and websites

Effective Interaction with Patients, 2nd ed [Faulkner A](#). New York : Churchill Livingstone, 1998.

Introducing Palliative Care 3rd ed. Twycross R. Abingdon : Radcliffe Medical Press, 1999.

Talking to Cancer Patients and their relatives. [Faulkner, A](#). Oxford: Oxford University Press, 1994.

A Guide to Symptom Relief in Palliative Care, 5th ed. Regnard C, Hockley J. Abingdon: Radcliffe Medical Press, 2004

Oxford Textbook of Palliative Medicine 3rd ed. Doyle D, Hanks G, Cherny NI, Calman K eds. Oxford : Oxford University Press, 2003.

CLIP

**Current
Learning
In
Palliative care**
An accessible
learning programme
for health care
professionals

Fifty seven 15 minute worksheets are available on:

- An introduction to palliative care (3 worksheets)
- Helping the patient with pain (9 worksheets)
- Helping the patient with symptoms other than pain (11 worksheets)
- Moving the ill patient (2 worksheets)
- Psychological needs (8 worksheets)
- Helping patients with reduced hydration and nutrition (8 worksheets)
- Procedures in palliative care (4 worksheets)
- Understanding and helping the person with alternative communication (learning disabilities) (5 worksheets)
- The last hours and days (4 worksheets)
- Bereavement (3 worksheets)

© 2004

Helping the Patient with Advanced Disease: a Workbook
Regnard C. ed.

Oxford: Radcliffe Medical Press www.radcliffe-oxford.com