

## CONSPIRACY OF SILENCE - HANDLING COLLUSION

From ethical point of view patients are entitled to receive as much information as they desire about their medical condition (diagnosis, prognosis, treatment ...). Collusion is unethical but is a universal phenomenon noticed amongst both Western and non-Western societies. Collusion implies any information (about the diagnosis, prognosis, and medical details about the person who is ill) being withheld or not shared among individuals involved. Collusion also means that relevant and complete medical information is selectively or not disclosed at all to patients and/or relatives. Medical teams often collude with patients' relatives to keep the former in the "dark" (e.g., please don't tell him/her about the severity of the illness), or the physicians colluding with patients (e.g., please don't tell my spouse or family about my disease), and not informing the family about the patient's diagnosis or prognosis. Major reasons for collusion are the widespread practice of physicians disclosing a diagnosis to a patient's family members before revealing it to the patient and clinicians' underestimation of the information needs of patients.<sup>2,3</sup> Clinicians may also regard collusion as an easier option than telling the truth because it reduces their own stress and anxiety.<sup>4</sup>

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1.	<p>Introduce yourself to the family member <b>Hello, I am doctor... And I am nurse .....</b> <i>(it is recommended to have two members of the team present in this discussion)</i> <b>And you are?</b> <i>(Let him/her tell his name. Avoid expressions such as "Are you Mr. Smith" could generate a false confirmation through an automated false answer of "yes").</i></p>	ESSENTIAL		
2.	Shake hands (if the family member wants to).			0 1 3
3.	<p>Find out who the person is and what the relation to the patient is <b>You came today to discuss about Mr/ Mrs ... (say the patient name). Can you please tell me who you are and what is your relation to the patient?</b> <i>(Avoid making assumptions like "Are you the wife?" – She might be a daughter or other and you can create embarrassing situations).</i></p>			0 1 3
4.	<p>Ensure the privacy for the conversation. - Shut the door after you put on the door the sign consultation in progress (or other way to mark that a consultation takes place in that room) - Patient in bed- draw the curtains around the bed <i>(Through proper communication you will build trust and you start by showing respect for the person in front of you).</i></p>			0 1 3
5.	<p>Reduce environment disturbing factors Turn off the radio, TV, cell phone (or ask your secretary to hold on calls). <i>(Educate your staff, other patients not to enter the room when a consultation takes place).</i></p>			0 1 3
6.	<p>Spatial arrangement a. Invite the patient (and caregiver) to sit. <b>Would you please take a seat?</b> <i>(There is a different time perception by the patient if you and he/ she are sited. The same amount of time is perceived longer when sitting compared with standing)</i></p>			0 1 3
7.	<p>b. Sit yourself. If patient is in bed take a chair and sit near the bed - <i>At a comfortable distance from the patient (about 1m)</i> - <i>The doctor's eyes should be at the same level with the patient's eyes (exception: when patient cries or is angry, the doctor's eyes should be at a lower level than the patient's eyes)</i></p>			0 1 6

	- <i>If patients come with relative/friend sit yourself in such a way to face the patient. At a closer distance from the patient that the friend/relative</i>				
8.	c. Remove barriers between you and patient - Move your chair to be next to the patient (better across the corner of the desk than across the full desk). - Clear the desk in the area near the patient <i>(Do not sit behind the desk, computer -nonverbally this is blocking communication)</i>				0 1 3
9.	d. Be prepared for patients/relative who cry Have a box of tissues nearby, just in case the patient or the relatives begin to cry; in that case, offer them tissues				0 1 3
10.	Body language. Take a neutral position that makes you look unhurried and relaxed - Feet flat on the floor - Shoulders relaxed; slightly lean forward - Friendly facial expression - Hands on the knees <i>(When you talk about difficult subjects like bad news, prognosis, patients fears, so on, you will feel uncomfortable but it is important that to train your body so that your nonverbal language appears calm and offers reassurance to the patient).</i>				0 1 6
11.	Starting the interview. Clarify the purpose of the family member concerning the present appointment. <b>Can you please tell me why you came to see me today?</b> <i>(at this point the family member will tell you something along the lines: that he/ she knows that the patient has cancer but "please do not tell him doctor the truth because he will lose hope and give up fighting the disease ....")</i>				0 1 3
12.	Acknowledge the collusion and then explore reasons <b>You've told me that you don't feel MR/MRS... name of the patient... to know what is going on. Why do you feel that?</b>	ESSENTIAL			
13.	Elicit all reasons for collusion <b>Have you any other reasons why you feel he shouldn't be told?</b>				0 1 3
14.	Use listening skills a. Use open questions (What...?, How...?, Why...? etc) that can be answered in any manner. b. Encourage nonverbally or with short sentence the patient family member / friend / next of kin to continue his ideas by nodding, pausing, smiling, using responses such as "yes", "tell me more" c. Be silent and do not interrupt the person <i>Listen to what the person says with words (content, tone) but also to the nonverbal communication (gesture, facial expression, body position...)</i> d. Maintain eye contact without being intrusive e. Clarify <b>"When you say...do you mean that...?"</b> <i>Gives the opportunity to expand on the previous statement or to emphasize some aspect of the statement when the clinician shows interest in the topic</i>				0 1 6
15.	Show you understand the reason for collusion and validate the reasons for it <b>Well you know him best and you could be right. It could be that if he's told he will ... you seem to have some good reason for him not being told.</b>				0 1 3

16.	Establish the emotional cost of the collusion on the family member / friend / next of kin <b>I now understand why you have kept the information from him, but what effect has this been having on you?</b>	ESSENTIAL		
17.	Be silent and listen to the concerns expressed by the family member / friend / next of kin. <i>(anxiety, difficulty keeping up with lies, barriers in communication with patient etc)</i>			0 1 3
18.	<b>Are you experiencing any other problems because of not telling him/her?</b>			0 1 3
19.	Summarize and move on <b>So, there are good reasons for trying to consider whether there's some way round this,.... make a summary of those reasons ( for example this situation puts strain on you, makes difficult the communication with your husband...). I would like to suggest how we might be able to do something about it</b>			0 1 6
20.	Seek permission to speak with patients <b>May I speak with the patient? What I'd like to do is to chat with him to see what he's thinking / understands about the present situation. It may be that he will reveal that he knows he has cancer (medical condition). If that's the case there will be no reason to maintain the pretence.</b>	ESSENTIAL		
21.	Establish the patient's level of awareness. If you do not know the patients first introduce yourself and afterwards ask an appropriate directive question which elicits his view of what is happening <b>I wanted to have a chat to see how you feel things are going? or What are you making out of what is happening to you ?</b>			0 1 6
22.	If the patient knows the truth – go to step 27 If patient does not know the truth or has an incomplete understanding of his medical condition – continue as follows Explore his willingness to find out more about the illness and stop there <b>Are you content with the information you have received concerning your illness?</b>			0 1 4
23.	If patient answer is YES this means now is not the right moment to break collusion If patient answer is NO – that means the patient wants more information – schedule a future appointment to discuss the diagnosis <b>I will look for you at the test results and other medical documentation that you have and will come back next time with more information</b>			0 1 4
24.	Explore other needs that the patient has ( <i>pain, appetite, mobility etc.</i> ) and offer management suggestions <b>Do you have problems related to the disease?</b>			0 1 4
25.	Inform family member about patient's wishes and offer to act accordingly <b>Your relative wants to know the diagnosis. I am prepared to break gently the news to him. Would you agree?</b>			0 1 4
26.	Tell the patient the diagnosis <i>(use the breaking bad news algorithm)</i>			0 1 4
27.	If the patient knows the truth but the family member / friend / next of kin is not aware For example: I've always known that what they've told me was a precancerous ulcer was a cancer) you now should confirm that he is right "I'm afraid you are right"			0 1 5

28.	Seek permission to convey his awareness to his family member / friend / next of kin, indicating that she/he knows the diagnosis. <b>Can I tell your wife about your understanding of the illness? She is aware of your medical situation.</b>					0 1 5
29.	Acknowledge the feelings expressed by patient <b>It sounds as if you might be feeling that it's no use to discuss because it won't make any difference to your situation.</b>					0 1 5
30.	Discuss your future involvement in care <b>It may help if we talk about how you're feeling and what you're worried about. It is quite likely there is something I can do to help you both for the physical or emotional suffering you experience.</b>					0 1 5
31.	Agree on a management plan and write down instructions for the patient. Check patients understanding. <b>Here are the written instructions tell me if you understand them. Can you please repeat them for me?</b>					0 1 5
32.	The closure of the interview An invitation to the patient to ask questions <b>Do you have further questions?</b>					0 1 3
33.	A clear arrangement for the next contact <b>I suggest the nurse calls to see how the treatment worked in 2 days and we meet again in one week.... How those this sound for you? ... Good bye see you next week!</b>					0 1 3
34.	Write the summary / conclusions of your discussion with the patient and his next of kin in patient file ( <i>by doing so all team members will be informed and will act accordingly</i> ).					0 1 3
<b>Total score: 120</b>		<input type="radio"/>				%
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		<input type="radio"/>				%

Legend:  - unfulfilled criterion;  - partially fulfilled criterion;  - completely fulfilled criterion

(score according to column P)

### Selective references

1. Peter Maguire, Ann Faulkner Communicate with cancer patients: Handling uncertainty, collusion, and denial BMJ 1988 VOLUME 297 15 OCTOBER pg 972-974
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3. Panagopoulou E, Mintzioti G, Montgomery A, Kapoukranidou D, Benos A. Concealment of information in clinical practice: is lying less stressful than telling the truth? J Clin Oncol. 2008 Mar 1;26(7):1175-7.
4. [James Alvin Low](#), [Sim Lai Kiow](#), [Norhisham Main](#), [Koh Kim Luan](#), [Pang Weng Sun](#), [May Lim](#), Reducing Collusion Between Family Members and Clinicians of Patients Referred to the Palliative Care Team Perm J. 2009 Fall; 13(4): 11-15.
5. [Santosh K. Chaturvedi](#), [Carmen G. Loiselle](#), [Prabha S. Chandra](#), Communication with Relatives and Collusion in Palliative Care: A Cross-Cultural Perspective Indian J Palliat Care. 2009 Jan-Jun; 15(1): 2-9