Journal of BUON **14:** 109-114, 2009

ORIGINAL ARTICLE

Informing the cancer patient and family

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Summary

One of the questions the therapist poses himself while informing a patient is: whom shall I inform about the diagnosis, treatment and prognosis? If we unconditionally accepted the view that information belongs to the patient from an ethical and legal standpoint, we would automatically exclude the partner and the family. Therefore, the therapist should raise another question: what is the benefit to the patient?

To answer the question and the resulting dilemma, we have to leverage the long experience of family therapy and tailor it to the cases we are dealing with. It should be taken into consideration that patient and family are a dynamic system which was balanced before the onset of the disease, but is now disrupted, entering into crisis.

Therefore, denial mechanism and personality characteristics we have previously elaborated on, and communication among members play a crucial role in determining the information strategy and the way family should be approached.

The steps to approach the patient - family are:

1) Firstly, we evaluate the patient's degree of denial and personality characteristics. Then we receive information about the patient's family so that we can have a rough idea about intrafamily dynamics.

2) Then we gather information from the nurses about the family atmosphere: simple information about the patient's and relatives' relationship like who comes to the hospital, who shows interest in the patient, whether someone is being quarrelsome or not are crucial to assess the dynamics of their relationships.

3) We summon patient and family members in our office.

4) We decide on the steps to inform the patient, and we apply them.

Involving family members with the patient seems to improve the results of information and forge concession and therapeutic alliance, which are necessary parameters in the therapeutic follow-up. Usually, doctors and nurses approach patient and family using their experience. Therefore, we need a training that will equip health professionals with the necessary knowledge to approach the family.

Key words: cancer patient, family, informing

Introduction

One of the questions the therapist poses himself while informing a patient is: whom shall I inform about the diagnosis, treatment and prognosis? [1]. If we unconditionally accepted the view that information belongs to the patient from an ethical and legal standpoint, we would automatically exclude the partner and the family.

Therefore, the therapist should raise another question: what is the benefit to the patient? [1].

We know that the patient is not alone; he has a family which is affected by his medical problem and which in turn influences the patient [2,3]. Family members are emotionally burdened during all phases of the illness and the everyday life balance is disrupted [4,5]. Informing the patient should not be an end in itself. Our actions should be focused on how to *benefit* the patient. If benefiting the patient entails involving the family as well, then we have a moral obligation to do so. Therapists often express their anger or get confronted with relatives. In addition, during relative seminars, nurses - more so than physicians - express their deep concerns about the patients' relatives.

Nurses come very close with the patient and fam-

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Received 02-06-2008; Accepted 10-07-2008

ily members. Nurses are also more accessible and, in a symbolic way, act in the same way as the patient's family [4]. A mother or a spouse for instance would look after her loved one by administering medication, feeding the patient etc. Nurses on the other hand do this professionally and their work is highly specialized. However, they can become either competitors or fellow-combatants. The physician on the other hand is more distanced. Usually, relatives too prefer that the physician be not involved in the patient's daily life, as if he were a power that should not be worn out, like a father figure [1].

To answer the question and the resulting dilemma, we have to exploit the long experience of family therapy and tailor it to the cases we are dealing with [6].

In serious medical problems, such as psychosis, family therapy concluded that family members can actually act as "co-therapists", by adapting the technique accordingly. Until then, the patient was either seen individually or family therapists would involve the whole family insisting on member equality and excluding individual approach [4]. Practice has shown that these techniques, even though theoretically sound, did not bring about the desired result. In both cases, the family was made to feel guilty and of course that would not help.

When faced with serious problems that bring about strong retrogression in a patient, involving the family members as co-therapists can actually achieve good results, whilst cooperation is achieved to the detriment of confrontation [7]. Thus, this could be a good technique for cancer patients but also for people who have suffered with chronic disease etc [8-12]. Of course, many therapists involve the family based on their own experience.

We will then give information and supply ways that we hope will enable the therapist to handle patient and family.

We ought to take into consideration that patient and family are a *dynamic system* which was *balanced* before the onset of the disease, but is now disrupted, entering into crisis [7,13]. The family, before the onset of the illness, had established a way of communication and members had distinct roles. Now, family members interrelate according to how they interrelated before the onset of the illness.

By *system* we mean a set of elements that interrelate and have a mutual effect on one another based on defined rules [6].

By *elements* we mean family members who interrelate and mutually affect one another. This relationship is dynamic and depends on each member's unique constellation of personality characteristics.

Thus, the family is in balance until an event (here the disease) disrupts this balance, or else, it is confronted with a crisis [7,13]. Once the family is confronted with a crisis, it manifests its "symptoms" that are expressed through the family's relationships.

In terms of patient informing, family participation and the therapeutic relationship with the family (patient plus members), it is very helpful for one to diagnose the patient's personality characteristics. Indeed, patient's and relatives' characteristics are crucial in their relationship.

Therefore, *the denial mechanism* and personality characteristics we have previously elaborated on [1], and communication among members play a crucial role in determining the information *strategy* and the way family should be approached. Knowing family member characteristics, especially the partner's, would also facilitate the task of informing. Still, this diagnostic process is not feasible in practice [1].

Once the diagnostic process with the patient is over, the therapist should summon the partner as well, and see how they interact. This would help understanding the dynamics in their relationship [6]. Then, the therapist should obtain information about the patient and his relations from the nurses who have daily contact with the family and patient and can describe in the best possible way the patient's routine. When asked to supply consulting care, the therapist must have a private discussion with the nurses. The benefit of this approach is both qualitative and quantitative [1].

When approaching a patient with his family, it would be helpful to picture the family as a body, a single system, an entity with its own characteristics in this dynamic relationship [6]. Our interventions should also respect this stance, whilst manipulations should have a positive reference. A confrontation with the relative(s) would be to no avail. In fact, relatives should be made partners, co-therapists (where possible) for the patient's benefit and the therapeutic relationship as a whole (therapist -patient).

The Family Approach

The steps to approach the patient - family are:

1) Firstly, we evaluate the patient's degree of denial and personality characteristics. Then, we receive information about the patient's family so that we can have a rough idea about intrafamily dynamics.

2) Then we gather information from the nurses about the family atmosphere: simple information about the patient's and relatives' relationship, like who comes to the hospital, who shows interest in the

patient, whether someone is being quarrelsome or not are crucial elements to assess the dynamics of their relationships.

3) We summon patient and family members in our office.

4) We decide on the steps to inform the patient, and we apply them.

Once we inform the patient privately, we meet with the patient and family in order to *communicate* such information to everyone concerned. This eliminates suspicion and doubt that the therapist has said something to one of the relatives that was not been disclosed to everyone. We should also take into consideration the *degree of denial* in the family, which is usually neglected because we believe that this mechanism affects only the patient. By careful observation though, we can see that the family can be also in denial, even though it is always informed about the diagnosis - even when the patient is not.

Family denial is manifested in various ways, inconceivable to us most of the times. Caught up in the belief that only the patient is in denial, we are frustrated with family reactions. This results in confronting them in order to protect our patient. We feel "as if the patient is a loved one that we have to look after" and that the patient's relatives are getting in our way. Yet, this confrontation is neither beneficial for the patient nor helpful on the whole for his care. The physician also considers that the patient is vulnerable, perhaps more that he actually is. This is communicated to the therapists usually by the words "don't tell him much", "he couldn't bare much" etc. This ultimately leads to overprotecting the patient and sometimes to even substituting the therapists' actions, especially those of nurses, whom they may regard as "not capable enough of looking after their patient".

The deeper fear of the relatives is that the patient will react with stress, panic or other reactions and that this will cause havoc to the family; a situation that family members will not be able to handle. A procedure of patient adjustment and acceptance would bring disruption to the rest of the members who have their own plans i.e. a member wants to further one's studies, another to expand one's business etc. These processes call for an "aggressive, extrovert action", whereas the patient's adaptation process calls for a degree of pondering and introversion to deal with this situation.

That is why family members prefer to be in denial, because they believe that disclosing everything would disrupt the family balance and jeopardize its development. It is therefore gathered that the family prefers a more distanced, hollow stance *that it can control* in order to maintain *family balance*. On other occasions, it can be expressed with questions about the fear of genetically transmitting the disease to offspring and avoid even to name the disease, as family members make a tacit agreement not to speak about the patient's problem.

The patient is usually urged to "stop thinking about it at all" as if "everything is fine" etc. Their attitude breeds denial. The patient interprets this attitude like the relatives want to avoid sharing the problem, that this is a burden to their routine. The patient also feels to be left alone and that he is made accountable for the disease's course when they say "give it a try, it all depends on you".

Family denial is often expressed by frequent visits to the therapists. They are constantly asking for reassurance and clarifications on what has been said as if there is still hope that something will change, that they will hear something different. This harasses or even aggravates therapists. At this point, therapists and the clinic team looking after the patient should be alert. Colleagues who participate in the therapeutic care as consultants should be even more alert. A mere change of wording by the physician could raise doubts in relatives. It often happens that when family members are in denial they tend to move the patient from that hospital into another.

Family denial can cause guilt and this further complexes the situation. In other words, they may react spasmodically either by indulging in money spend or by looking for magical solutions or even taking the patient to various charlatans.

This approach *eases off family denial*. This is overall beneficial for family members, facilitating therapeutic alliance and rendering family members co-therapists, partners and not opponents.

Let us have a look at some of the "*symptoms*", namely, manifestations of a family:

A) We have made a brief allusion to *overprotection.* It is expressed in various ways, such as a constant encouragement of the patient to eat even though he cannot, when the partner wants to feed the patient himself. The patient is constantly asked if he is well, if he feels tired, if there is something they can do for him. It has been reported that the husband would bring flowers to his wife, something he never did in the past and her mother would wake her up when she had a rest asking her if she was feeling well.

Overprotection aggravates patient retrogression and dependence. The patient may feel useless, he may suspect that something worse is happening to him, he may lose his spirit that one day he will be autonomous again.

As we have already reported, family approach may have a positive effect. Objurgation, no matter how well intended, is to no avail.

Overprotection occurs i.e. when these overprotection manifestations are the result of an exaggerated interest to the patient. We also note “any overexaggeration”, whereas we note that the same interest may be manifested with a less pressuring way and bring about better results. We could also urge the family to admit that they can cooperate better and possibly ask for the therapist’s help i.e. if the medium of overprotection is food, to agree on which meals the patient would like, to distribute it in smaller portions etc.

B) Another “*symptom*” of the family that aggravates the tension is based on the *difficulty to communicate* fear, thoughts and emotions among them [14]. Usually those fears and thoughts exist in both sides but are not communicated to each other, thinking that they are protecting one another and *vice versa*. There could exist fears of death, suspicions about the seriousness of the illness etc. It is only natural that when such fears stay hidden, they assume greater proportions in imagination. If we take the steps we previously described, communication is facilitated and such an outcome is prevented. If such fears are deeply seated, they can be solved by mitigating stress, tension and reducing member isolation.

Manipulations should be performed in the presence of the patient and family or at least of the partner; yet, in practice this is not feasible. The therapist serves as the facilitator to restore communication. It is him who will recapitulate on common thoughts, common fears among the members and soften matters. Therapists are often concerned about what will happen when common fears come to light. The family wants to be facilitated by the therapist.

C) The situation for the family is difficult when the patient is in the stage of *anger,* meaning that he is being quarrelsome and aggressive [15]. The therapist’s approach here consists in *looking at the bright side of things* [14] by saying to the relatives that this shows that the patient seeks their attention, wants them to turn their interest to him. At the same time, the therapist communicates to the patient that he overexaggerates, that he can express himself about the same things in a milder way without inhibiting the expression of emotions.

D) Another point that is usually neglected or is taken for granted, or even considered redundant is to explain and make the family understand the crisis which they are confronted with [2,4,15]. The therapist explains to the family that prior to the onset of the disease everything was balanced, which means that there were positive and negative elements but everything could work out. Now the balance has been disrupted and they are in confusion. The therapist can explain using plain words i.e. that everything was going well before the disease but now things have changed because of the disease and hospitalization. Now they have to find a new balance, a way of doing things. In order to accomplish this goal the therapist should assure the family members that he would be there for them to find the best solution. This makes the family feel that if the members have a good collaboration among them and cooperate with therapists, a positive result could be attained. Thus, the family can cope better with the threat caused by the disease of one member, the tension is diminished, the fighting spirit springs back up and a better adjustment process is achieved.

E) To that end, we might also need to offer *practical advice* i.e. when relatives rush to the hospital all together, thinking that this will help better. The therapist says that they can help the patient when they carry on like before; that they should schedule their visits to the hospital, continue with their activities and even enjoy themselves. Even when all these are not feasible, the relatives learn to remove the guilt away and are functioning better [1].

Such interventions should exclude families with the so-called paranoid functioning. By paranoid functioning we mean a situation marked by quarrelsomeness, an acute projection of aggressiveness of one member towards the other. Such a case calls for a specialized therapist with a good experience in family therapy.

By knowing the degree of denial in the patient, the degree of denial in the family (they often are similar), the patient’s personality characteristics and the relations within the family we can attain a better therapeutic relationship and provide better information for the patient. Denial and personality characteristics of the patient and family manifest in various ways. We will try to refer to some indicative examples, which will serve as guides in the process of disclosing information.

A patient with depending characteristics will most likely leave all manipulations with the family. Such a patient would not ask the therapist directly about the medical problem or he would do it timidly, without insisting or just for the sake of asking. The family that “knows” this will pose questions, will not inform the patient or provide a vague diagnosis that has been some times agreed with the therapist as well i.e. an inflammation, a virus, a cyst that has not become a malignancy yet etc. The family and the partner in particular, would become overprotective by assuming all responsibility. The partner usually has controlling-organizing characteristics or emotional characteristics (hyperthymic or hypothymic) that help protect the partner [1].

The above fragile balance is even more aggravated when the medical problem persists after revealing an agreed upon diagnosis. Then the partner feels an enormous burden, becomes even more overprotective, feeling angry with the patient, urging him to do this or that, to eat so that he can get his force back.

The controlling patient wants to know, wants to learn and tends to eliminate everyone else from the disclosure. The partner and the family can accept the patient's behavior or, to a bigger or lesser degree, they could act similarly. The full mosaic of the relationship dynamics is now revealed and we have to deal with any versions of these dynamics. Tension is usually present, conflict as well, when the family intervenes and the patient is not informed properly. As we have already stressed, doubt and anxiety become more acute. Therapists feel that these families are putting obstacles in their way, create havoc, so they get angry about their overprotective attitude. Communication within the family can be aggravated when the patient feels an intense degree of doubt and becomes distrustful about anything that is being said.

If the partner has depending characteristics, the patient will cede the manipulations to the controlling partner. The patient will assume the entire burden but will then get angry when he feels the need to lean on someone.

The above mentioned course of action will minimize adverse effects. Even an agreed vague diagnosis is better to be communicated in the presence of the ill person and the partner (and the family).

We could describe a number of characters, denial and dynamics combinations. But we think that by knowing and pondering on these factors one could have a full view of the patient, the family and the therapeutic relationship.

The best and more appropriate way of knowing and deepening on these problems and manipulations is to discuss and interact within a team of therapists. This can also be done in the context of a Liaison Psychiatry collaboration at a personal level. But the team has an important advantage coming from interpersonal learning through the experiences of members. The advantage is obviously both qualitative and quantitative.

Conclusion

Involving family members with the patient seems to improve the results of information and forge concession and therapeutic alliance, which are necessary parameters in the therapeutic follow-up.

Usually, doctors and nurses approach the patient and family using their experience. This approach is effective. Especially nurses are in a more advantageous position, since they have daily contact with the patient that is they know who is paying visits, what conflicts emerge, they are more entrusted with their problems, so they have a more accurate knowledge of family dynamics. Doctors and nurses find it hard to cope with crisis and often confront the relatives. This obviously has a side effect: they are not made partners, co-therapists for the sake of the patient. The same health professionals declare that they are not adequately trained to inform and that such training is absolutely vital [16-18].

Therefore, a training is needed that will equip health professionals with the necessary knowledge to approach the family [1,4].

Training is theoretically based on experiential exercises such as role playing [19,20]. When this training is combined with collaboration upon exercising Liaison Psychiatry in the hospital, it can be effective [20].

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