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Reinventing life and death: discourse in intensive care units

Introduction

This article focusses on the discourse features and dynamics of exchanges between the professional staff of Intensive Care Units (ICU) and families of patients in critical conditions and beyond. We are specifically referring to patients who suffered severe head injuries caused by a trauma (accident) or a sudden medical event (aneurysm). Due to the nature of these patients' condition, interaction with their families must be carefully managed, particularly in situations when the string of 'bad news communication" culminates with an announcement of brain death followed by a request for organ donation.

Research on the donation consent process has focussed primarily on when the donation request should occur; who should approach the subject with the family; where the conversation should take place (Malecki and Hoffman 1987, Prottas and Batten 1988, Randall and Marwick 1991, Chapman et al, 1995). More recent work has identified variables in the request process which affect the decision to donate: the family's level of information, the manner in which brain death is communicated, and the extent to which the family's questions are answered by hospital staff. (Romano et al. 1990, Marwick 1991, Franz 1997, Shafer et al. 1997, First 1997, Sirchia 1996, Sirchia and Mascaretti 1997).

There is clear evidence that donation conversations which are incorrectly planned and directed are highly likely to result in refusals (Pottecher et al. 1993, Raper and Fisher 1995, Stein, Hope and Baum 1995, Nuss at al. 1996, Waissman 1996, Bonnet et al. 1997, Gortmaker et al. 1998 Verble and Worth 1998). Several studies indicate that when the request is made by personnel specifically trained to use appropriate protocol, terminology and timing, the donation rate almost doubles (Lopez-Navidad et al. 1997, Gortmaker et al. 1998, Siminoff et al. 1995). A good deal of attention has therefore been devoted in recent years by organ procurement organizations to the preparation of training programmes which provide ICU personnel (physicians as well as nurses) with adequate education and practice on how to conduct a fruitful donation request discussion.

The present research focuses on a different phase of the doctor-family relationship, that is on the sequence of exchanges which pre-date the donation request, from the very onset of the patient hospital admittance to the declaration of brain death. It is during this crucial "waiting period" suspended in time that the relationship with the family must be nurtured in order to establish a rapport based on trust, confidence and mutual respect. This will enable the family to accept and understand the difficult concept of brain death, and subsequently, through the elaboration of their loss, deal with the crucial decision to donate.

The Methodology

The data for this investigation were collected in hospitals in three different Northern Italian cities in the context of workshops designed to train healthcare professionals in communicating effectively with families of potential organ donors. The organization of these workshops included presentations by trainers, group discussions, problem-solving sessions, and role-playing simulations followed by debriefing sessions which included an evaluation or a critique by a team of psychologists, pedagogical consultants and experienced doctors. All sessions were video and audio taped.

Training workshops were, and still are, the only source of data accessible to researchers. The use of "real" data with "real" interactions between ICU personnel and families is unfortunately impossible for ethical reasons, due to the private and emotional nature of the event. The role plays are designed so that the trainees (doctors and nurses) play "themselves", re-enacting familiar language in well-known scenarios, while the members of the patient's family are played by well trained actors who intentionally introduce "problematic" features, such as a passive or aggressive behaviour, an inability to listen and understand, or a tendency to control the exchange. These elements are introduced to test the doctors' communicative competence and to observe their repertoire of reactions. In short they are well designed "booby traps" which have to be recognised, avoided, dealt with and mastered. Role-plays are very valid learning tools as they allow to identify and focus on specific problems, to find alternative solutions, and to generate more precise descriptions of linguistic behaviour and discourse features. They train ICU personnel to master a well memorised routine and deliver it in a seemingly spontaneous manner.

The Data

Once transcribed, the data were analysed according to a qualitative framework which identified two different kinds of discourse features in the performance of the ICU personnel: Hearer Supportive (HS) and Self-Supportive (SS) discourse features. Previous research on accusatory complaints, compliments, interruptions, and refusals defined as HS features those which support the face of the hearer and as SS features those used by the speaker to support his/her own face (Frescura 1995,1996a,1996b,1997a,1997b). In the specific context of this research, we identify as SS discourse features those used by the speaker to remove possible concerns over guilt and blame associated with delivering bad news, as for example interruptions, technical jargon, topic control, while we define as HS discourse features those used by the speaker to guide the family toward understanding and acceptance, as for example hesitations, repetitions, reformulations, or open questions (Frescura 1999) The transcription and

analysis of three role-play extracts follows below Due to space restriction, the text of the original Italian data could not be included together with its English translation . To facilitate reading, transcription conventions were not employed, with the exception of single square parenthesis indicating interruption and simultaneous speech.

Extract n. 1

Situation

A man is seriously injured in a car accident. His wife, with him in the car, is unharmed. The man is taken to the nearest hospital, but in view if the seriousness of his situation, he is transported to a larger and better equipped hospital. The wife (Mrs. X) is in the waiting room when a doctor from the ICU approaches her :

1.D: Mrs. X? Good morning, I [am Dr……..

2. W: [At last….. I have been waiting for quite a while….

3. Doctor: Well…. we had some problems with another… as you know…Mrs. X…. your husband…. has been ….
taken….. transferred …. to [our hospital after….

4. W: [Well…. I don't understand…… they sent me here…. I am here and … I have
been here for a long time..

5.D : Have you already spoken to someone, Mrs. X..?

6. W : No… I didn't speak to anyone…. there is nobody here….. they told me to come here, that's all…..
they told me…. that ….there are….. serious problems…..

7. D: Yes, that is what I would like to …….. Mrs X, …could you tell me about the accident? What happened
exactly?

8. W: Well, we were driving and all of a sudden.. I don't know….. the car started to zig-zag, we were… (she
cries) .. a short trip…. (she cries) , then the ambulance came and… (she cries)…

Pause (5 seconds)

9. D: Are you alone, here?

10. W: Yes, yes, alone."

Pause (3 seconds)

11. D: Do you live in the area?

12. W: …..but we have some friends not far from here …

13. D: Mrs. X, perhaps you will feel better…. You'll be more comfortable…. if you come into in our lounge….

Analysis

This extract presents from the very onset some clearly problematic discourse features and it can be divided into two separate parts: the first one from turn 1 to 6 in which the wife takes full control of the exchange and the second part from turn 7 to 13 in which the doctor with careful use of HS discourse strategies is finally able to redirect the topic and build a more symmetric relationship. In turn 2 Mrs. X interrupts the doctor's introduction and takes immediate control of the exchange, establishing an asymmetric rapport with him. She speaks loudly, and her tone is cold and annoyed. In turn 3 the doctor reacts to Mrs. X's accusation trying to explain the reason for the delay. Understanding that further elaboration will fuel Mrs X's aggressiveness even further, he quickly resorts to a repair strategy, redirects the topic, and tries to regain control of the exchange by focussing on her husband's situation. He also tries to include some piece of "shared information" in order to break the communication barrier (as you know...).

In turn 4 Mrs. X continues to control the topic interrupting the doctor and repeating her accusations. In turn 5 the doctor asks a yes/no question in another attempt to master the exchange. In turn 6 accusation continues. At the end of this turn Mrs. X introduces for the first time a new element by referring to the accident (serious problems).

In this first part we see a discourse with a circular structure, as there has been no exchange of information between the doctor and Mrs. X due to her lack of co-operation on one side, and on the doctor's use of SS discourse features on the other. In turn 3, for example, he tries to defend himself from Mrs. X accusation (we had problems with another..) and in turn 5 he asks a useless question, demonstrating that he had not been listening to what Mrs. X was saying in the previous turns (I have been waiting.. I have been here for quite a while..) Moreover, during this first part of the exchange the doctor spoke quickly and avoided eye contact with Mrs. X.

Turn 7 marks the beginning of a new HS oriented approach. The doctor had been listening to what was said in turn 6 (serious problems) and asks an open-ended question which requires a more elaborate answer from Mrs. X and which will put an end to the circular discourse structure. In turn 8 Mrs. X is finally able to stop focusing on

herself and to start facing the topic of the accident. In turns 9 and 11 we see that the questions asked by the doctor are the result of very careful listening on his part. He did pay attention to the words “short trip” in turn 8 and understood that Mrs. X was away from home, alone and scared. He realised that she was a “patient” as well. By listening to her, the doctor successfully built a more linear exchange as can be seen in Mrs. X’s co-operative replies in turns 10 and 12. In the last turn 13, the doctor feels that the situation has stabilised and invites Mrs. X in a more private environment where he could inform her of the seriousness of her husband’s condition. In this last part the doctor slowed down the pace of the exchange, paused for several seconds, and kept eye contact with Mrs. X while really listening to her to gather the necessary information to successfully get out of the impasse created by her topic control. Throughout the exchange the doctor made repeated use of the form of address “Mrs. X” thus giving an empathic and personal dimension to his communication.

Extract n. 2

Situation

A young man (19 years old) is severely hurt in a motorcycle accident. He has been in the ICU for 36 hours. The doctor meets with his parents for the third time to keep them informed of the situation:

1. D: We called you for this meeting in order to keep you informed of your son’s present situation… last night we explained to you that he had been operated and that the situation seemed somewhat more stable ….. unfortunately during the night there have been some complications and at present the situation is much more critical than last night….

2. Father: But he was already… [I was under the impression….

3. D: …[his condition has deteriorated from both the encephalic and the cardiac point of view…. his coma is a very deep coma….

4. Father: But we don’t….

5. D: [the most important thing is that you are kept informed and you are prepared and it is for this reason you have been called here… at present we are running some more tests, blood work, and an MRI which is a test to understand if the brain is still working, and then we can give you a more definite answer in the next few hours… we’ ll call you as soon as we have more news….

Analysis

The narration protocol followed by this doctor is articulated into three separate units:

-recapitulation of previous information known by parents (antecedent) in turn 1;

-introduction of new information regarding changes in their son’s prognosis in turn 1 and 3;

-delineation of future plans for action.

There is also the introduction of a pedagogical element, as the doctor clearly explains to the parents what the function of an MRI is (turn 5). In spite of all these positive HS discourse features, there are obvious problems as the asymmetric structure of this exchange is not at all the structure of a dialogue, but that of a well memorised monologue, of a written text, of a script delivered to a passive audience. We also see that parents are not given any opportunity to participate and express their concerns as the doctor’s discourse style does not allow for transition points where the parents can insert their turns. She holds the floor, ignores the fathers’ interventions (turn 3 and 5) and continues her narration without any attempt to modify the delivery of her pre-fabricated text. Among the several Self Supportive features contained in this extract is the repeated use of the personal pronoun “we” which not only covers and protects the doctor (“I am not the only one responsible for these decisions”) but also isolates and excludes the parents (“you are not one of us”). There is also a lack of empathy and special attention to their feelings and their anguish (the important thing is that you are kept informed) in turn 5. The pace of the delivery was very fast without any trace of hesitation or reformulation which is typical of spoken language and especially of difficult and emotional communication.

Extract n. 3

Situation

A 22 year old man, victim of an aneurysm, has died. The ICU doctor announced his death to his parents, explaining to them that he was brain dead, and that his body was still warm and appeared to be breathing because he was artificially ventilated. He did not tell them that this protocol was applied so that their son’s organs could be kept viable in view of a potential organ donation. Preparing himself and the parents for this request, the doctor talks again to them one hour after announcing their son’s death, with the purpose of verifying their level of acceptance and understanding of what brain death means:

1. Mother: Doctor, do you believe in miracles?
2. D: Mrs X, you are asking me if a miracle is possible for your son?

3. Mother: well,…. yes..
4. D: No, Mrs X , brain death is irreversible…
5. Father: …yes but,…. you know,…. don't you read the papers, ?…
6. D: You are referring to those people who wake-up, right?
7. Father: hummm,…. yes,… we often read that…
8. D: this is question that … I deal with very often…. eh, yes, I read the newspapers and unfortunately… I see that not only the people who read them but also those who write the articles don't know the difference between coma and brain death…. of course it is possible to wake up from certain types of coma…. the people you are talking about never had a total absence of activity in the brain…. but for your son…….for him….. I already explained…. for him there is a total lack of blood circulation in his brain …… which means that the brain is dead…… and when there is no brain…...there is no more life…

Analysis

In this exchange we see a very strong Hearer Supportive discourse style. The mother's question in turn 1 reveals that

the parents have not accepted or understood brain death and are still in the negotiation phase (Kubler-Ross 1969,1989). This signals to the doctor that he cannot proceed at this time with the donation request. In turn 2 the doctor answers by reformulating the mother's question. A reformulation strategy is a well known tool for establishing a symmetric relationship between the interlocutors, as well as a well disguised topic control strategy. In this specific case the total question (yes/no) helps the mother to focus on the subject matter, and contributes to narrowing the field of enquiry as there can only be a "yes" answer (turn 3) to which the doctor replies without hesitation or elaboration (turn 4). In turn 5 the father's tone is sarcastic and aggressive and his question hints at the possibility of a mistake, puts in doubt the doctor's professional competence, showing that the parents are still in the negotiating phase. Once more the doctor reformulates the father's question in turn 6. In doing so he legitimises the father's doubts and keeps the channels of communication open and symmetric. In turn 8 the doctor starts by universalising the problem and recognising that the father's concerns are shared by others and are not to be dismissed. The doctor takes the opportunity to carefully explain once again the difference between coma and brain death and to guide the parents through the process using a language adapted to their level of understanding with transparent images and a syllogistic approach to "re-citing the evidence" (Buckman 1992, Maynard 1998). In the second part of the turn the doctor speaks slowly, making short pauses between each step of his explanation in order to give the parents the time to focus their attention and to assimilate the message. It also signals that this is not a memorised routine, but a message delivered with careful empathy by a doctor who provides support in the first initial stages of the grieving process.

Conclusions

The present research represents the first study of the interaction between ICU practitioners and patients' families from a discourse analysis perspective. Moreover, such analysis has never been carried out in an Italian speech community. This research had the following objectives: 1. to gain insights into the discourse features used by ICU practitioners in communicating bas news to their patients' families; 2. to identify discourse features which are of crucial importance to the fruitful outcome of a possible organ donation request; 3. to identify discourse features which could jeopardise the outcome of the request. The data analysed revealed a number of Speaker Supportive discourse practices which signal the "dispreferred status" (Levinson 1983) of bad news communication and show that doctors are often uncomfortable and defensive: speaking too fast and too much, holding the floor, ignoring or interrupting the interlocutor, and using the pronoun ('we') to partly dissociate themselves from the information being communicated.

A number of Hearer Supportive discourse practices, more conducive to a successful exchange with a patient's family, emerged as well: careful monitoring of the amount of information given to the family, approaching the topic with empathy and sensitivity, allowing the family to ask questions and express doubts, respecting their turn-taking rights, and using the personal pronoun "I" to assume full responsibility for what is being said. The dissemination of these observations will be of interest not only to discourse analysts in general, but also to healthcare professionals as these findings may well suggest useful guidelines for fruitful communication.

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