

Breaking Bad News to Families of Dying Children: A Paediatrician's Perspective

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1. Introduction

"The death of a loved one is a highly emotional and stressful experience for families and the death of a child, in particular, is one of the most painful bereavements for families and also for professional care givers." (Stevens, 2004) According to Fallowfield, "The physicians' behavior and communication of caring and competence at the end of life are known to have a major influence on the ability of patients and families to assimilate the news, consider options, and adapt and adjust to what lies ahead." (Fallowfield, 2004) It follows therefore that communication at the end of a paediatric patient's life is an important area of general paediatric practice.

1.1 Deaths in childhood

The mortality rates in childhood show a wide difference globally. In India, the under-5 mortality rate in 2009 was 66 as compared to 6, in the UK. Infections and malnutrition are the leading causes of deaths in India while accidents, congenital anomalies are the main causes in the UK. (UNICEF) This chapter has been written based on a recent study by the authors in the Paediatrics department of a tertiary general hospital in Mumbai, India.

1.2 Relevance of the study

The study is relevant not only to palliative care but also to the field of Pediatrics because the overall aim is to obtain an in-depth understanding of the perspectives of resident paediatric doctors about factors that affect the communication of the child's actual or impending death to the family care givers. In Palliative medicine as a specialty, much emphasis is laid on the provision of high-quality physician-family communication at the end of life. Palliative care professionals can be instrumental in offering constructive criticism about communication issues in other specialty settings like Paediatrics. A study by Pan et al. clearly showed the presence of a palliative care service improved the confidence of fellows in end of life care. (Pan et al., 2005) As one of the primary aim of paediatric palliative care is "the provision of care through death and bereavement" (Association for Children's Palliative Care/Royal College of Paediatrics and Child Health, 2003), a study of the perspectives of resident paediatric doctors about breaking bad news to families of dying children is clearly relevant to palliative care.

1.3 Background

Previous studies have identified some of the factors that affect the process of communicating the death news to the paediatric patient's family. These factors may be broadly divided into those related to the doctors, factors related to the patient and the family and to factors in the work environment.

A qualitative study by Contro et al. from a Children's University hospital, in an urban setting (Contro et al., 2004) described the perspectives of families of deceased children and of staff members of the hospital and community physicians, on the quality of Palliative Care. The study employed two diverse approaches- family caregivers of children who had died at the hospital were interviewed on a face to face basis while staff members and community physicians filled up a written survey. Communication between staff and families of dying children was one of the problem areas marked by the staff members who reported feeling "inexperienced" in communicating with families about end of life issues. Lack of experience was associated with feeling distressed in communicating with families and patients. Staff members perceived that "emotional, psychological and social support was lacking or nonexistent" within their work environment. "Personal pain and the lack of support" were related to staff members' most difficult experiences of caring for dying children. Majority of the staff members including 85% of the residents said that they would "welcome consultation with a palliative care team."

A part of the same study which relates to the experiences of bereaved families has been published in another paper. (Contro et al., 2004) Sixty-eight family members of 44 deceased children were interviewed by clinical social workers and a psychologist. The views of the families corroborate those of the staff members- feeling distressed due to uncaring delivery of bad news and careless remarks made by staff members and lack of support from the staff. Besides non-English speaking families reported that the language barrier greatly affected their ability to comprehend the information given by the doctors. The above study explains the relevance of preparation, language, staff training and support to how resident doctors communicate with families of dying children. In a study from another specialist paediatric centre in the USA, Kolarik et al. also demonstrated the lack of effective palliative care training in paediatric residency programmes; the authors attribute this to the absence of specific mentorship and role modeling during their residency and to the absence of a formal palliative care service in the hospital. (Kolarik et al., 2006)

Clark, in a lucid commentary outlining specific concerns about residents' and interns' training in a neonatal intensive care unit, points out to factors in the work environment that affect communication between residents and families. (Clark, 2001) He identified long work hours, lack of clear institutional policies and doctors' fear of litigation which negatively affect interactions between them and parents of dying children. The doctors' personal attitude that death is an enemy leads to inappropriate therapies and "distancing" behaviour with the parents.

Previous interactions of the residents with the family and the patients are also known to affect their manner of breaking bad news. Sahler et al. interviewed 31 interns after the death of a child in their care so as to understand the factors that determined their interaction with

the patient and his family. (Sahler et. al., 1981) The authors identified that the major patient related factor that determined their interaction was the ability of the children to have a meaningful interaction which was dependent on the child's age and neurological status. The interns failed to develop an active relationship with parents of children who were unable to interact with them. The interns' relationship with the parents of the dying child was affected by the duration of the child's illness- having cared for a long time for an ill child helped the intern to understand the child's place in the context of the family and also increased their empathy towards the parents when it became clear that the child was dying. Interns "actively avoided" parents of children who died suddenly sensing the hostility that parents felt towards the interns.

Previous studies have identified some significant factors that are likely to affect communication with families of dying children. We believe that a qualitative research methodology based on the grounded theory will enabled us to obtain an in depth understanding of the subject.

None of the above studies specifically explored the issue of breaking the news of the actual or impending death of the child to the family. The practice of death declaration is one of the most sensitive areas in general paediatric practice and one in which research is greatly lacking.

It became clear from the review of existing literature that the factors which are likely to affect the practice of breaking bad news to families of dying children. These factors were explored in our study.

1.4 Objectives of the study

The overall aim of this qualitative study was explore the perspectives of Paediatric resident doctors about breaking bad news of the actual or impending death of a dying child to the family, in an urban Government run general hospital in Mumbai, India, with respect to the following.

- Physician related factors e.g. training, experience and knowledge and attitudes
- Patient related factors such as age, gender, cognitive ability or type of illness, duration of care provided
- Family members' characteristics such as gender, educational status
- Environmental factors within and outside the residents' work such as patient load, availability of space and privacy, support

2. Study methodology

This was a qualitative study based on the grounded theory approach. Strauss and Corbin, define qualitative research as "any type of research that produces findings not arrived at by statistical procedures or other means of quantification. It allows the investigator to research about persons' lives, lived experiences, behaviors and emotions." (Strauss and Corbin, 1998) In Health care, qualitative research methods have been applied to study subjects such as the organization of health services, interactions between doctors and patients, and the changing roles of the health professions. (Pope and Mays, 1995)

The qualitative research method was suitable for the present study as it allowed the investigators to obtain an in depth understanding of the topic and to interpret data in terms of the meanings attached by the residents.

The investigators used a naturalistic inquiry process in which they attempted to discover the perspectives of the residents without affecting any change in the environment. Data obtained through “naturalistic inquiry” manner is more likely to reflect the “real world” situation. (Patton, 2002) The interviews were conducted by MD who was unknown to the residents and did not work at the site of data collection. This decreased the bias that the interviewer brought to the interview process. The tool for data collection was the semi-structured interview which was based on the interview guide. This type of interview allowed the interviewer to explore in depth and ask questions to illuminate a particular subject *within* each topic area specified in the interview guide.

The sample for the study was drawn from the pool of Resident doctors in the department of Paediatrics at Lokmanya Tilak Municipal General hospital, Mumbai. These resident doctors included those who were in a residency program either a post graduate degree (MD) in Paediatrics or a Fellowship in Pediatrics. The points of divergence were- gender, current posting (ward, paediatric intensive care, neonatal intensive care), marital status and being a parent. These specific points of divergence were included as each of these characteristics was thought to have an effect on the communication with families of dying children. Residents who had declared death a family at least once during their training were included in the study. Even though the expected sample size was approximately 10, seven interviews were conducted as thematic saturation was achieved within this number having met all the points of divergence.

Prior to starting the study, the proposal was ratified by the Institutional review board of the first author’s host institution and the Human Ethics committee of the Institution where the data were collected. Each participant received the “participant information leaflet which contained the details of the study. They were given a ‘sleep over time’ of at least twenty four hours prior to obtaining a valid consent. All the interviews were conducted on site by MD. Five interviews were recorded on a digital audio recording device. For two respondents who refused audio recordings, notes were taken during the interview. Demographic data were collected at the time of the interview. These included age, gender, marital status, number of own children and any personal bereavement in the past two years, average number of occasions when bad news has been broken by the doctor.

The interviews were transcribed verbatim and narratives were written for each respondent on the basis of the interview, demographic data and any additional notes made by the interviewer during the interview. Confidentiality was ensured by keeping the consent forms separate from the data sets. The narratives were analyzed for emerging subthemes by MD and MM.

3. Results

Three major themes emerged from the data- Practice, Attitudes and Interpersonal relationships. The major themes were divided into subthemes as follows- Practice- Preparation, Language, Setting and Training and Support

Attitudes- Emotional responses, Coping, Influence of personal life, Roles
Interpersonal Relationships- Resident- patient relationship, Resident- family member relationship.

We discuss each theme in detail in the section below.

3.1 Main theme: Practice

The theme Practice addresses the actual practice of breaking bad news in the study setting.

3.1.1 Preparation

Preparation refers to the communication between the doctors and the families prior to the declaration of the patient's death. The content of this communication revolves around giving information about the clinical condition, ongoing treatment and mentally preparing the family for the child's death.

The following is an example of how doctors "prepare" the families to receive the bad news.

RD6: "The usual practice of breaking bad news is..... when a child is serious; the poor prognosis is explained to the family. We explain what the problem that the childthen what we are doing to improve the child's condition. We explain in such a way that they realize that everything possible is being done to salvage the child. If the child continues to deteriorate and finally dies, the family is explained that despite the maximum medical support, the child could not be salvaged."

Giving detailed information is considered important for gaining the trust of the family, which in turn facilitates breaking bad news. Families must have sufficient time to prepare themselves mentally to hear the bad news; families who have not had enough time to come to terms with the impending death, experience much psychological distress. The other reason that emerged was that the doctors felt that the family would "blame" them or become "aggressive" if they were not adequately aware of the efforts being made by the doctors to save their patient's life as is evident from the above response.

The setting of the Neonatal Intensive Care Unit (NICU) is different as compared to the general ward setting. RD5, a registrar in the Neonatal Intensive Care unit points out to the distress of families suffer while having to face an unexpected turn of events when a newborn is admitted to the intensive care unit. She says-

RD5: "And a... it's like especially in NICU it's like a small baby and it's a generally like a time of joy when they know that the baby has been delivered now and so but instead of that if they get this news that the baby is really sick and....."

Thus preparing the families is emphasized by all residents so as to gain trust, allow time for the family to be mentally prepared and to avoid blame.

3.1.2 Language

Patients from diverse socioeconomic, linguistic and educational backgrounds are treated in the present study setting. The sub theme language looks at the way the doctors use

language to effectively communicate with families of dying children from such dissimilar backgrounds.

According to the doctors, families with poor educational backgrounds are unable to grasp certain medical terms that may be used in the context of the patient. Hence given the importance of communicating appropriate information, resident doctors emphasized the use simple terms while conveying information about the patients' crucial condition to the families who are often poorly educated.

Also relevant to the subtheme "language" is the exact use of words that the doctors use to describe the dying patient. Some of the descriptors used are "serious", "things going out of hand" and "not going to make it" rather than using the word "dying".

RD1: "We never saying "dying"- even after the first cardiac arrest we say that we are doing everything ventilator, injections....."

RD7: "I tell them whether the patient is serious I usually tell them before hand that you know that like the patient is getting serious, you know, things are getting out of hand. We don't know there are very less chances of his survival and we are trying our best. "

Most of the doctors preferred not use the term "dying" to describe the patient's condition but rather to use various euphemisms to convey the information. The one respondent who would actually use the word "death" while preparing the family probably had enough rapport to explain the situation and the prognosis to the family beforehand. He would use the actual words "possibility of death" while talking about a future outcome.

Sharing a common language with the family is viewed as an effective tool for rapport building with the family. The doctors and the patients come from diverse linguistic backgrounds as the hospital in which the study has been done is located in a large metropolis in India.

To summarize, the subtheme "language" focuses on the use of simple, non medical words while informing poorly educated families about the patients' condition and ongoing treatment. The use of terms such as "dying" or "death" is considered inappropriate by all but one of the doctors. Sharing a common regional language with the family helps doctors to build rapport in the setting where there is significant linguistic diversity.

3.1.3 Setting

The subtheme "setting" includes the perspectives of the resident doctors about the various factors within the local environ, that affect the way they break bad news to the families.

All the respondents pointed out to the limitations of resources they faced in their setting. These included lack of availability of beds in the intensive care unit and limited financial resources of the families. Limited human resources in relation to the number of patients are also viewed as a problem which affects the work. Some of the following examples illustrate these problems.

RD1: "The problem here is that other municipal or government hospitals often do not have vacancies and the private setups too expensive for our patients. In such a situation patients

end up in the ward where they die. Also since Sion is a tertiary hospital, patients come here in a bad shape”.

RD2: “Unfortunately in other places like the ICU it becomes difficult (To break bad news) “- due to the design of the place, constraint of space.”

All the doctors acknowledge that the lack of availability of beds on the Intensive Care Unit does affect the care delivery to the patients. Limitation of space also compromises the privacy that is needed while breaking bad news to the family.

Limitation of human resources means that the doctors often do not have fixed duty hours. The setting of the study is a busy Paediatric tertiary unit catering to thousands of patients annually. The resident doctors have a very busy work schedule. The following examples provide an insight into the work that they put in during their training as resident paediatricians-

RD1: “In my first post I worked without off call for 3 months ---”

RD7: “we used to have work like anything in Sion Hospital..”

Overall the resident doctors’ work during their training is quite grueling. Despite this, the respondents felt that it may affect other areas of their work but not the way they broke bad news.

Within the subtheme “Setting”, the impact of the institution’s policies on the doctors’ practice is discussed in the subsequent paragraphs. The doctors are bound to follow certain institutional procedures which affect their interaction with the family of the deceased child. One such procedure is related to having to ask for a mandatory post mortem examination when a patient dies soon after getting admitted. This is viewed as a particularly distressing process for the grief stricken family.

Currently, there are no clear policies about withholding futile treatments.

RD5: “a...what Dr. M. (senior neonatologist) feels that we should give them (all babies who are critically ill) 100 percent chances and put him on the ventilator and try our level best. But from whatever I’ve seen I’ve like baby 700 gms I don’t think that we should really be aggressive... depending on how preterm the baby is.....being really aggressive to save the child at the cost of all the other babies especially in our setting.”

RD5’s response reflects her feeling that scarce resources must be used optimally and the policy of resuscitating every neonate, irrespective of the outcome may compromise care for other patients. RD3 who is a Fellow in Haematology and Oncology also felt that the likely prognosis should determine the priority the patients receive for their treatment.

RD3: “But what happens ki (that) when we have a..’N’ number of children, and we have to prioritize a few....So definitely we would like to prioritize the ones who are salvageable.”

To summarize, the doctors’ practice is guided by the policies and procedures of their institution. They perceive some of these procedures, such as seeking the bereaved family’s consent for a post mortem examination, as unduly distressing for the family and to an extent, even for the doctors. The issue of appropriate policies about resuscitation of neonates at the edge of viability and just allocation of scarce medical resources based on the prognosis was also discussed here.

The question "What kind of changes would you like to see in your setting about the practice of breaking bad news?" elicited somewhat similar responses from all the doctors. One area of change was related to having a "designated person" to support the families after bad news was broken to them. However there were some differences in the perception of the exact role of this person.

RD3: "There is no emotional support in our part of the setup and it is definitely very important.....That emotional support maybe some counselors should be there."

RD6: "Ummm.....The overall practice of breaking bad news is good as it is.....but it is better to have a dedicated social worker or counselor for the PICU. This individual can support the bereaved family immediately after the patient's death."

Residents would value a dedicated person who would provide emotional support to the family while the doctors should be the ones to break the bad news. Three of the respondents also pointed out to the need for private space where families may receive bad news.

3.1.4 Training and support

In this subtheme, the level of training that the resident doctors have in communication skills, specifically in end of life issues, is discussed. The support that is available for doctors from staff members in their institution and colleagues, while communicating with families about crucial issues, including breaking bad news is also described under this subtheme.

General communication skills workshops are conducted for the resident doctors in the study setting for the past three years. These workshops include didactic teaching and discussions. Not all doctors have completed this training- in fact only five out of the seven doctors interviewed have completed the training. The training has been in the form of "stand alone" teaching sessions without any refresher or follow up sessions. The impact of the communication skills training was perceived quite variably among the residents. While one of the doctors who had not received training himself but had seen his juniors being trained felt that they were fortunate to have been trained formally in communication skills. He said-

RD1: "The new batch of residents is lucky- they have orientation communication training etc. We had to learn on our own."

RD4 had received some communication skills training at the centre where she worked previously. She felt that the formal training that she had received was good but she could not incorporate the skills into her routine practice. She said-

RD4: "Ya it was helpful, but that I forgot after that. I didn't practice...didn't practice much."

It is evident that the even though the doctors had received some formal training in communication skills the impact of such training on actual practice was not significant. One of the reasons could be that most of the doctors had been trained in "stand alone" sessions without any follow up or reinforcement and this may be a possible reason why the impact of the session on practice was insignificant.

Besides formal communication skills training, other sources for learning also emerged-such as studying for foreign medical examinations, books and television. Observing senior colleagues and faculty members as role models and experiential learning were the other

important ways of inculcating communication skills. Nurses were also considered as a source of support in difficult situations of breaking bad news. This is an example where the supportive role of nurses becomes evident-

RD6: "Nurses do not directly declare death but they help by supporting the female family members like the mother or the grandmother. They talk to the family, call other family members who may not be in the hospital at the time of death and give first aid to the bereaved person if required."

The presence of a "mob" of relatives is perceived as a threat and the presence of security personnel at the time of death declaration was considered to be appropriate. This opinion is the result of the episodes of abuse that resident doctors have faced in the recent past in the centre where this study has been carried out.

In summary, training has minimal effect on the practice of breaking bad news to families of dying children. Senior staff members as role models and one's own experiences are important sources for learning communication skills. Staff members like nurses and security personnel are supportive in difficult communication situations.

3.2 Theme - Attitudes to death of children

The main theme "Attitudes to the death of children" was divided into the following sub themes-Emotional responses, Coping, Influence of personal life and Role.

3.2.1 Emotional responses

All the Resident doctors perceived the death of their patient as "saddening". In fact RD2 describes the death of the patient as "devastating" while RD3 admitted that he "felt depressed" following the death of a paediatric patient. The respondents also pointed out that their reactions to the deaths were more intense during the initial part of their training but over the course of time, the intensity of their emotional responses has diminished and that they have come to accept deaths of patients as an inevitable part of their work. The following is an illustration of this point:

RD3: "At a personal level ..umm..actually during the initial part of my training I used to feel a bit depressed but a..Gradually over the years I am training I have gone to several institutes. I have seen multiple deaths." "deaths are bound to happen and we have to accept it that is what I have realized over several years of my working".

Thoughts about the death of a patient affect the resident doctors' work for some period of time but having to get on with the tasks of caring for other patients is a distraction. An example of this is given below:

RD2: "Over a period of time you can get into the care of other patients that is the best thing to do..get into your work, dedicate yourself to your work..and may be in an hour or two you can be totally out of it."

Respondents whose interaction with the patient was more personal were emotionally more affected by the death of that patient. Also a longer period of caring and a better rapport with

the patient or the family led to the death being viewed as saddening. Specifically, playing with the children was viewed as a “bonding activity”. Excerpts from interviews highlight this point.

RD2: “As a paediatrician, there is a tendency to get bonded with the patient. May be that is there in medicine also but it is more so in paediatric age group. We play with those kids and it does affect you mentally somewhere.”

RD4: “we are...we are also emotionally attached. The small babies... we means.... play sometimes with them and chat with them; they suddenly go bad so.....really we feel bad.”

RD6: “When the patients are suffering from a chronic disease, they have a long follow up. So we become more attached to such patients. When such a patient dies we feel worse. There was a leukemic girl who was not responding to treatment. We knew that she was dying but felt that she should not die. We had made a lot of efforts to let this child to pull on.”

One of the respondents, RD6 perceived that doctors may make greater efforts to save the life of a particular patient to whom they have become “attached”.

Six out of the seven respondents mentioned that they “blamed themselves” for the death of the patient when they were unable to save the life either due to lack of medical resources or due to their clinical inexperience.

RD1 who is a registrar in the Paediatric Intensive care unit said that, “I feel bad when a patient who is salvageable, dies because there were no resources. I feel bad at a personal level.... like I have the knowledge but am helpless..... Sometimes it is depressing..... I try not to blame myself for the death.”

All the respondents mentioned that they reflected about each death clinically and tried to understand what could have been done differently. RD5, a junior registrar in the Neonatal Intensive Care Unit, mentioned that the Mortality meetings in the Neonatology department every month were helpful in this respect.

To summarize, Paediatric resident doctors view the death of their patients as saddening. The emotion was stronger when the residents had become “attached” to the patient. They also experience some guilt about the death of patients but consider each one as a clinical learning opportunity in their practice.

3.2.2 Coping

The busy ward and large number of patients under their care helps the doctors to take their minds off a patient’s death.

RD5 points out to lack of time –“We don’t really keep thinking about it there is so much happening that you can’t really sit and think about one patient that you’ve lost. We don’t get that sort of time here.”

Four out of seven respondents said that they spoke to friends or family members when they were upset about a patient death. It was particularly helpful if the person were a doctor as they felt that such a person would understand them better. Watching movies or going out with friends also helped.

There is no formal structured support for resident doctors who may face emotional distress as a result of their work. To illustrate the point, excerpts from the interview with RD3 are given below.

RD3: "For Doctors, (laughs), it will take a hundred years to happen, in India."

Another respondent felt that staff members actually offered support and advice to the resident doctors about patient deaths. In this regard, he said that-

RD7: "I am down after a patient's death, madam sees ___ why you are worried. This is you know just part and parcel of life. So---yeah, obviously I do get support from all of them. "

One of the respondents volunteered that being spiritually inclined helped him keep his peace of mind and get on with the numerous roles he had to play on the professional and the family front.

To summarize, the resident doctors coped with patient deaths in different ways. The most common mechanism was to become involved in caring for other patients. The lack of formal mechanisms for psychological support in the work place was recognized but senior staff members were viewed as being helpful. Watching movies, talking to family or friends and spirituality were also considered helpful in coping with the deaths of paediatric patients.

3.2.3 Impact of family life

In this study specific factors related to the family lives of the residents were explored to ascertain whether they had an influence on the practice of breaking bad news. A general question to this effect was "Sometimes, factors in our life, outside our work environment may affect our work. Do you think that there are any such factors that affect your communication with families of dying children?" Specific prompts were used to elicit issues regarding the influence of their family lives on their professional practice.

RD1 had experienced a recent bereavement and also had a close family member who was suffering from advanced cancer. RD1 appeared uncomfortable while answering this question but he acknowledged that on certain occasions his personal experiences may have affected how he broke bad news to the family. However he tried consciously to prevent this from happening.

RD7 is the only doctor in the setting who has a child. He thinks that he may become more "emotional" while breaking the news of death of a child to the family because he is able to identify himself with the parents of the patients.

All the other respondents were asked a hypothetical question related to the issue- "How do you think having one's own children would affect the way in which they broke bad news to the family?" The male respondents were not sure whether having their own children would make a difference to the practice of breaking bad news. The remaining two female respondents were divided in their opinion- one of them felt that there would be a difference in the way they broke bad news while the other (RD5) felt otherwise.

RD5: "Umm...in the medical a...field I don't think it would make a difference because we've been trained and groomed over the so many years. It doesn't make so much of an impact."

From the ongoing discussion, it is evident that doctors' communication with families is affected by certain situations in their personal life, however they make a deliberate attempt to keep their personal and professional lives separate.

3.2.4 Roles

Here we discuss the doctors' perceptions about the role that they play in the care of the paediatric patient. The doctors view that their main responsibility is to be involved in the physical aspect while the psychological care is largely considered to be outside the scope of their job.

The following examples illustrate the doctors' views about their role in care giving.

RD3: "I strongly feel that this (psychological support) is one domain where this one thing is that clinicians don't have so much of time as I told you."

Even though residents realize that psychological support is important for bereaved families, they would not be in a position to do so themselves because the doctors are too busy. Besides, the task is viewed as both time consuming and emotionally taxing. Residents would rather hand over the care of dying patients to another professional care giver.

RD3: "So I would like ki (that) maybe I can invest more time in the ones who..(Pause 2seconds) In whom I may get the fruit out of my efforts rather than those in whom I know a... that my limitations will not allow me to take the child for long."

While the above response reflects RD3' s personal opinion about caring for children who have poor chances of survival or improvement, his comment also highlights the ethical issue of distribution of scarce resources in his local setting. This issue of resource availability is further elucidated in the theme "setting".

Like the above two respondents, RD4 a female registrar in the NICU, puts her feelings about breaking bad news as follows-

RD4: "Ya it's the worst part. I hate that means I hate I *literally hate* it I can do every work. I can do as much hard work as I can but I hate means declaring to the patient and writing a Death Certificate."

The reason for RD4' s aversion to breaking death news of neonatal patients is probably related to the fact she has been in this setting for several months, at a stretch, without respite from frequent patient deaths which happen.

Overall, the doctors regard breaking bad news of the patient's death as an emotionally draining task. They also acknowledge that due to constraint of time, they would rather entrust the task of providing emotional support to the families to another professional, a specialist in caring for dying patients and their families, while they would invest their energies in caring for patients who are more likely to get better.

Only one of the doctors mentioned the term "Palliative care" to describe the care that dying patients should receive. This respondent, unlike others, is probably aware of palliative care because he has worked in a large cancer institution which has a specialist palliative care

team. This fact clearly points to a lack of awareness about palliative care among the doctors. However the descriptors used by the others to describe the desirable care for dying children, are actually related to the essential principles of palliative care practice indicating the need for palliative care provision in this setting.

3.3 Main theme-Interpersonal relationships

3.3.1 The patient

In this sub theme, the perspectives of the doctors about the paediatric patient, within their role as professional care givers and outside that role, are described. The impact of these perspectives on the practice of breaking bad news to the families is also described.

Children, even as patients, are viewed as endearing and innocent by the respondents. Here are some of the responses to the question "How are paediatric patients different from adults?"

RD2: "Their innocence..ya ..unlike adult patients may vocalize to you all findings ..there may be some abstract things affecting you but in the pediatric age group....even pain for that matter..if a child is in pain he will immediately vocalize it out...while an adult might keep it subdued."

Doctors share the view that the loss of a child who is able to talk and to communicate is viewed as greater than that of one who is not able to do so, both by the doctors and by the families. The following are some examples that illustrate this view point-

RD1: "Children who are about 4-5 have cognitive abilities.... They are able to communicate..so the bond of these children is more than with very small babies."

RD6: "Families react more intensely when an older child dies."

The child's ability to communicate appears to be central to the bonding that families and even the doctors share with the child. The other aspect that doctors consider important while developing a "bond" with their patient is when they play with the patient. This is discussed in detail under the subtheme "Role".

Within their practice, the doctors often have to care for children whose limited cognitive ability precludes any meaningful communication. The doctors agreed that patients with abnormal cognition are unable to communicate well and hence it is difficult to "bond" with them; however these children are still considered to be "special".

RD2 says, "No even those -you may not be having interactive sessions but you will feel sorry -humanity comes in the picture. You feel that as it is he is in pain, as it is he is dying, unfortunately he cannot vocalize. So then you get puzzled-what is the best thing you can do."

Most doctors felt that the gender of the patient makes difference while breaking bad news because the reactions of families were likely to be stronger when it was a male child rather than a female.

RD2: "Ya at least in our community it does to be honest.....we have seen that at times if it is a female child people are accepting while if it is a male child, people might create a lot of.....we have seen that at times ya so at least in the Indian setup it does."

RD5: "a...first of all a...when you tell them the sex of the baby that might be a problem if it's a female child. A...specially there are no male children already there in the family so that's kind of like really sad to know that they still feel like that of girl child and all that."

The doctors witness gender discrimination against the female child, by the family, within their practice setting. They also point to specific situations or groups where such discrimination is more likely to occur.

RD1: "Rarely, in cases of neglected children or orphans with HIV, neglected children with cerebral palsy- female children were at a disadvantage."

RD2: "On the other hand there may be someone from the lower socioeconomic strata who are desperately wanting a male child and that particular male child is sick then they will be affected more....."

A child who is socially "at risk" is more likely to face the brunt of gender discrimination. Only one of the respondents RD5 remarked that she was saddened by the discrimination; the other doctors seemed to look upon the issue as inevitable fallout of the general societal norms in their setting.

Neonates are a specific subgroup within the paediatric patient population. Two of the doctors interviewed were working in that unit at the time of their interview. Their perceptions about their very young patients are presented here-

RD5: "And a... it's like especially in NICU it's like a small baby and it's a generally like a time of joy when they know ki the baby has been delivered now and so but instead of that if they get this news that the baby is really sick.."

In the NICU the patients are often brought in almost immediately after their birth. In this scenario, the anticipated joy turns into a stressful situation for the family, as is evident in RD5's response.

RD4: "Clearly means it feels like as if a part of our family member is going it's like that only...(pause 1 second)...Because it really feels bad. It feels like all our hard work is wasted and we are...we are also emotionally attached. This small babies we means play sometimes with them and chat with them they suddenly goes bad so really we feel bad."

RD4's response gives an indication of the sense of loss that she herself feels when a newborn baby dies. Playing with the patient emerges as a source of "bonding" once again from RD4's response.

To summarize, the paediatric patient is perceived quite differently from the adult. The doctors find themselves becoming emotionally attached to their paediatric patients; the child's ability to communicate is an important factor in developing this attachment. Even children who are not able to communicate are considered to be special and the doctors are more sympathetic towards them. The doctors recognize a difference in the manner in which families react to deaths of children, depending on their gender. This is probably considered as an expected outcome of the existing societal attitudes. In case of the newborn patient, the family often witnesses a joyous situation turn into a stressful one and for the residents; the "involvement" with these young patients seems to be more marked.

3.3.2 The family

The practice of breaking bad news to the families seemed to depend to a large extent on the expected reactions of the family members and on the previous interaction between the families and the doctors. The expected reactions described by the doctors ranged from acceptance of the child's death to anger and aggression. The following are examples of the different reactions described by the doctors.

RD7: "They talk about everything you know... how much care they have taken about this child. What that child meant to him or to her or to them. And yeah I mean they really break down I mean.... They were through a lot and when they see this I mean obviously you know the sky breaks for them."

RD3: "The most important thing which I have felt the parents feel is that, they feel that they have not done enough for the child because they are, usually the patients at Sion Hospital are very poor non - affording kind, So they feel that they a.. a lot of time there are financial constraints. When they are not able to arrange then they feel guilty that because of not getting this medicine my child expired. So that guilt feeling... if I'm able to take it out from their mind that is also a big achievement so that life long they should not feel guilty "That our child expired because we could not get the medicine." So I generally make them understand that if you even tried to get the medicine the disease was such and a.. the child was so sick that a.. we have limitations, we are not God."

Grief and guilt are common reactions of the families to hearing the death news. However families may sometimes respond with anger directed at the doctors. The following are some examples-

RD2: "They were always under the impression that whatever happens however bad our child is he is going to come back again ..but here accepting the fact that the child had died.....the dad became very volatile."

RD2: "They are so used to hospitalization, child deteriorating, going to intensive care and coming back. So might be somewhere they have this idea that this is a routine thing. And this particular thing happening-child not shifted to the ICU but dying in the ward....so they might feel because of those elements not happeningso they start comparing- this time the child was not sent to the ICU. So was it a mistake on part of the doctors?"

The doctors have experiences- their own or those of their colleagues where family members have become aggressive or abusive. All the respondents who mentioned such experiences attributed them to the family's lack of mental preparation for the death or of their denial of the possibility of death.

Conversely, doctors find that trust and having a good rapport with the family facilitate breaking bad news. The following examples illustrate this point.

RD6: "Most of the times, the families accept the situation because they generally trust the doctors."

RD7: "I have a lot of rapport with all of my patients since beginning since I was the houseman. The patients, their relatives tend to relate with me. I tend to listen a lot that is one

way. I have seen many resident doctors have altercations with the family but I never had to face that problem. So if you have that rapport things become easier."

To summarize, lack of acceptance of the bad news and aggression by the family are the difficulties that the doctors face while breaking bad news. It was "easier" to break bad news to families which trusted the doctors or with whom the doctors had a good rapport.

3.3.3 Gender

All the respondents felt that the gender of the family member to whom they broke the bad news affected their practice. All but one of the doctors remarked that they would rather avoid breaking the bad news to female relatives in general and to the mother specifically. RD1: "I do not break news of death to female relatives like the mother or the grandmother. We usually tell male relatives like the father or the grandfather."

RD3: "And therefore he (the patient) is there like that, so it was easier for the parents to accept or the whosoever is receiving this death news. It would be easier for him to accept. And then I would tell them that a..a they should first take care of the mother and console her properly and then slowly break the news to her."

RD4: "Umm... so initially whatever happens to the newborns na we keep on informing to the relatives. A...not to the mother usually to the male relatives."

RD6: "I try to avoid giving bad news to the mother unless there is no one else. I would try to break bad news to male relatives like the father or the grandfather."

All the above responses reflect reluctance to break bad news in general to the female relatives and in particular to the mother of the deceased child. Some reasons are evident from these responses-

RD3: "In India definitely it makes a difference because a... females maybe they are not able to accept the news so early this is particularly about death news I am telling. Whereas males..... they, means they try to understand a situation, they're not so emotionally labile particularly at that moment so I prefer first telling to the male member so that they can dilute it and then convey it to the other members of the family including females."

RD5: "Ya...a...that's just because the bond unknowingly whatevereven if the mother has not been with the baby.....since the baby was born. But a...we don't really want the mother to collapse or something just hearing the news that the child is no more."

The strong emotional response expected from the mother is a deterrent to breaking bad news directly to her. On the other hand, men are perceived as being more composed and in control of the situation. The doctors therefore prefer to break bad news to the male family members.

While the gender of the family member was an important factor in breaking bad news, the gender of the doctor who broke bad news did not seem to affect breaking bad news to the family, in the opinion of all but one of the respondents.

In the present study setting, there are many patients who come from poor socioeconomic and educational background. Each doctor was asked whether the educational level of the family made a difference to breaking bad news. All of them felt that the level of education of

the families variably affected their emotional responses to the bad news but made a difference in how they perceived the patient's condition.

RD3: "Ya...ya it affects a lot because a... a...because what happens...depending on the literacy level they have other beliefs also, like a few families are there who feel that some other therapies and some other faith healers or ayurvedic (traditional Indian medicine) and like that."

RD6: "When the families are poor and there are several children in the family their reaction to the death may not be very intense, in fact they may not be too bothered by it. A poor family who has a past experience of losing a child may not be too bothered by another child death."

RD7: ". Sometimes uneducated people will you know accept it, some educated people will not accept it."

To summarize, the educational or socioeconomic levels of the family may affect their understanding of the patient's condition prior to death. Poor families with a previous loss of an offspring may react less intensely to the bad news. Lack of education may also lead families to refuse medical treatment and to opt for traditional therapies or faith healers thereby endangering the patient's life.

The significance of the gender of the family member became clear as all but one of the doctors expressed reluctance to break the bad news to the patient's mother. This may reflect the doctors' unwillingness to handle strong emotional reactions or their perception that providing support to the female family members who were viewed as more "emotional" was not a part of their job. The educational level of the families has a variable impact on the way that the resident doctors break bad news. The less educated families are viewed as more "accepting" in their attitude.

4. Discussion

4.1 Main theme: Practice

The descriptions of the resident doctors about the actual process of breaking the news of the death of the child to the family were quite similar. All the respondents emphasized that the families must be "prepared" to receive the news of the child's death in a gradual stepwise manner. The doctors usually begin by explaining to the family the nature of the child's illness and his present clinical condition and then go on explain in detail the measures and treatments that are being done to save the child's life. "Preparation" emerged as an important subtheme within the main theme "practice". Preparation referred to - giving the family time to come to terms mentally with the reality of the child's impending death, making the family aware of the ongoing treatments and helping the family members to understand the limitations of doctors and medical interventions in prolonging the child's life.

Preparing the family was seen as an important step towards gaining the trust of the family members and doctors found it easier to break bad news to families who trusted them. The doctors believe that families who receive the news of the child's death without any warning

suffer greater psychological distress. When families understand that everything possible is being done to save the child's life, the chances that they will blame doctors for the patient's death are reduced.

The residents stressed the need to not merely convey information to families but also to use language that the family members could comprehend. Most families who receive treatment at the centre of the study often come from poor socioeconomic backgrounds. They are unable to understand medical terms. Hence the residents make sure that the words that they use while explaining the situation to the family are common terms used typically by the people. The residents consciously avoid using medical jargon while speaking with patients' families.

The centre of the study is in a cosmopolitan area where people often come from other parts of the country to find a livelihood. Hence the patients coming here are from diverse linguistic backgrounds and sharing a common language with the family is thought to enhance rapport building. In contrast, a language barrier is a major obstacle to conveying information effectively.

There is reluctance to use the term "death" or "dying" and this probably reflects a general reluctance to openly discussing issues related to death, among the common people as well as the residents in our study setting.

Some factors in the local environment that affect the process of breaking bad news to the families. Despite grueling work hours and lack of time for self care, none of the residents feel that these factors affect the way they break bad news to the family. Certain institutional procedures that have to be followed after the death of a patient are perceived to be distressing for family members. Among the changes that the residents would like to see in their workplace as regards to the practice of breaking bad news are- adequate privacy for the family and a designated person to provide psychological support to the bereaved family.

Five out of the seven respondents had received some formal training in communication skills but none of them found that it affected their practice. Stand alone training sessions without follow up were ineffective in producing any change in practice. Informal methods such as learning from one's own experience and by observing senior staff members as role models were considered to be important in learning communication skills.

Nurses are viewed as playing a supportive role in caring for families of dying children. Some of the residents find it desirable to break the news of death to the family in the presence of security personnel-reflecting that the residents sometimes feel threatened by the families.

4.2 Attitudes

The emerging subthemes here are- Emotional responses, Coping, Influence of personal life and Role.

The residents describe feeling saddened by the death of the paediatric patient, one of the residents reported feeling "devastated" by the patient's death. These emotional responses are more acute during the initial part of the residency training.

Residents felt sadder when they had a better rapport with the patient and the family or had been involved in caring for a longer duration. Playing with the children was seen especially as a bonding activity. One respondent observed that residents may make heroic efforts to save the life of a child to whom they had become attached.

All the residents reflected on a patient's death as a professional learning experience.

The doctors coped with patient deaths by becoming involved in caring for other patients and by talking to their friends and family members. Even though there was no formal mechanism to support the doctors emotionally, senior staff members were sympathetic and this seemed to help the residents.

Residents acknowledged that experiencing a recent personal bereavement or having one's own child probably affected the way they broke bad news to the family; however they consciously tried not to let their personal feelings affect communication with families.

Residents perceive that their main role in caring for the patient is restricted to the physical domain and providing emotional support is seen to be secondary due to lack of time and the emotionally taxing nature of the task.

The need for an additional service that supports families facing the death of child is expressed by all the residents. This may well reflect the felt need for palliative care in the study setting.

4.3 Interpersonal relations

The relationships that the residents form with the patient and the family affect the way that they break bad news of death to the family. Children are considered to be "endearing" unlike adult patients. A child's ability to talk and communicate typically around the age of 4-5 years, increases the bonding with the child. The loss of such a child is considered greater than that of a preverbal child. Even though children with cognitive deficiencies are unable to communicate much with the doctors and the families, such children are considered to be special and evoke more sympathy than other patients. The loss of a neonate is felt more acutely by the residents possibly because they feel that a time of anticipated joy for the family turns into grief.

Residents remark that the loss of a male child is considered by some families to be greater than the loss of a girl child. The attitude is more prevalent among poorer uneducated families where the male child is valued for his potential to add to the family's earning. For the doctors themselves children of either gender are equal. Children who are socially "at risk" are more likely to face gender discrimination. The discrimination against the girl child witnessed by the residents in our study is part of a general societal trend in the country which has seen a falling sex ratio over the past few years.

Factors related to the family which affect death declaration are the expected emotional reactions of the family members, the gender of the family member to whom the bad news is broken and the socioeconomic factors. Doctors are better able to deal with families who trust them and accept the situation as against those who seem to deny the reality of the loss and become aggressive or abusive. All the respondents have either themselves been involved in or have seen colleagues been involved in situations where family members have become abusive.

There is almost a uniform reluctance to break bad news to the female relatives specifically the mother of the child as the mother is expected to become very emotional on hearing the bad news. On the other hand, men are perceived to be in better control of the situation and it is easier to declare death to male relatives.

Some families from a poor socioeconomic background may not be able to fully understand what is going on with the patient. These families may sometimes refuse proper medical treatments and instead go to faith healers. This can be frustrating for the residents who may be unable to save the child's life. However there are often poor families who can comprehend most of the information given to them by doctors as long as medical jargon is avoided.

Based on the above discussion we were able to identify relationships among the various themes and subthemes. As the data were analyzed simultaneously with further data collection, certain emerging themes from the preliminary interviews were explored further in the subsequent interviews. For instance, the strong reluctance to declaring death to the patient's mother emerged in the very first interview. Even though we had included "gender of the family member" as one of the prompts in the interview guide, we probed further about the residents' perspectives of breaking bad news to the mother in subsequent interviews. Thus "iterative approach" allowed the investigator to refine data collection based on emerging themes fits the paradigm of grounded theory. (Lingard, et al., 2008).

As data collection and analysis were done in tandem, comparisons within data sets were made constantly. For example, the subtheme "preparation" emerged prominently within the data sets and there was uniform emphasis on preparing the family prior to death declaration. One of the "background assumptions" when we started the data collection was that formal training in communication skills would help residents in breaking bad news to families of dying children. The responses showed that there was divided opinion about the value of training. A closer look at the data showed that the doctors who thought that training was useful were in fact those who had not received the training themselves but presumed that it would be helpful in dealing with families. Hence we conclude that training in communication skills was not helping residents to break bad news to families of dying children.

Interrelationships among the various themes and subthemes emerged and are described in the subsequent paragraphs.

The subthemes "preparation" and "language" are interrelated and are in turn related to the subtheme "Family" as follows. Both the subthemes preparation and language refer to communicating information about the patient's critical condition in a manner that the family can understand. Gaining the families' trust or failing to do so is determined by the efficacy of the doctor-family communication. Families that do not trust doctors may become aggressive or abusive. Thus effective communication is indirectly related to the family's expected reactions to the bad news.

In the subtheme "Roles", it emerges that even though residents believe their role in care giving is mainly limited to the physical aspects rather than the psychological, the need for having an additional person(s) for providing support for families was recognized and a recommendation for such was noted in the subtheme "setting". The subtheme "Roles" is

also connected to the subtheme "Patient". When residents see themselves outside the role of professional caregivers, they tended to develop a more personal involvement with the patient e.g. by playing with the child.

Support from senior staff members, categorized under the subtheme "Training and Support" was linked to the subtheme "Coping" as it was considered helpful in dealing with patient deaths. Feelings of sadness or guilt after a death was included in the subtheme "Emotional responses". The various measures that the residents took to overcome these feelings such as sharing with family members or friends were described in the subtheme "Coping".

Predictably enough, personal experiences of bereavement or parenthood seemed to make residents more emotionally sensitive while breaking bad news. Hence the subthemes "Influence of personal life" and "Emotional responses" are interconnected.

5. Limitations of the study

The results of this study are context-specific and hence may not be generalizable to other settings, where patterns of patient load and medical resources may be different. The results of the study are influenced by factors such as the socioeconomic background, gender issues which are characteristic of the patient population served by the centre.

We did not attempt to validate the research findings as it was considered beyond the scope of the present study.

A paediatric palliative care service is in the initial stages of establishment at this centre and this is likely to significantly change the residents' perspectives of breaking bad news to family caregivers of dying children.

6. Future research

This study has helped in identifying several factors which affect communication between resident doctors and families of dying children. Findings from this study may be used to develop a quantitative measure which may be used across similar settings to gain an understanding of the important end of life communication in the general paediatric setting.

It would also be interesting to repeat a similar study in the same setting so as to assess the impact of the new paediatric palliative care service.

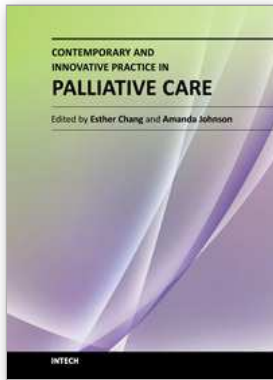
7. Conclusions

The process of breaking bad news of the death of the paediatric patient is an important area of practice. A number of factors which affect this process have been identified in this study. The findings of this study can form the basis of further research on the topic and can be used to develop recommendations for improving communication between resident paediatricians and families of critically ill children.

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Contemporary and Innovative Practice in Palliative Care

Edited by Prof. Esther Chang

ISBN 978-953-307-986-8

Hard cover, 302 pages

Publisher InTech

Published online 10, February, 2012

Published in print edition February, 2012

This book is designed to provide a comprehensive insight into the key and most prevalent contemporary issues associated with palliation. The reader will find viewpoints that are challenging and sometimes discerning, but at the same time motivating and thought-provoking in the care of persons requiring palliation. This book is divided into three sections. Section 1 examines contemporary practice; Section 2 looks at the challenges in practice; Section 3 discusses models of care. This book is an excellent resource for students, practising clinicians and academics. By reading the book, reflecting on the issues, challenges and opportunities ahead, we hope it will create within the reader a passion to take on, explore and further develop their palliative care practice.

How to reference

In order to correctly reference this scholarly work, feel free to copy and paste the following:

M. P. Dighe, M. Marathe, M. A. Muckaden and M. Manglani (2012). Breaking Bad News to Families of Dying Children: A Paediatrician's Perspective, Contemporary and Innovative Practice in Palliative Care, Prof. Esther Chang (Ed.), ISBN: 978-953-307-986-8, InTech, Available from:
<http://www.intechopen.com/books/contemporary-and-innovative-practice-in-palliative-care/breaking-bad-news-to-families-of-dying-children-a-paediatrician-s-perspective>

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