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THE DOCTOR AND THE DYING CHILD

DISSERTATION PRESENTED FOR THE DEGREE OF MASTER OF
PHILOSOPHY IN CHILD AND ADOLESCENT PSYCHIATRY

DEPARTMENT OF PSYCHIATRY AND MENTAL HEALTH
UNIVERSITY OF CAPE TOWN

MARCH 2003

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ABSTRACT

AIM

South African doctors are confronted with a growing population of terminally ill children every day. Research pertaining to doctors facing a dying child is limited. Qualitative methods were used to gain insights into the impact of a dying child on doctors' feelings and functioning in their professional and personal life.

METHODS

Individual interviews and one focus group were conducted with 8 senior paediatric registrars from Red Cross Children's Hospital. The content of discussion was coded, categorized, followed by a sequential analysis and deeper descriptive analysis before drawing and verifying conclusions.

RESULTS

Six themes emerged: 1) doctors' attitudes towards a fatal illness; 2) training and teaching around death and dying; 3) doctors' interactions with a dying child; 4) doctors' relationship with the parents of a dying child; 5) doctors' feelings, defences and coping styles while managing a dying child; and 6) emotional support for doctors.

CONCLUSIONS

A dying child and the quality of doctors' relationship with a dying child and his/her family impacts on the doctors' feelings, professional and personal coping styles.

Cultural differences, ethical dilemmas, work load, decision making processes, hospital and national economics are significant stressors influencing the quality of care of a dying patient and his/her family.

Doctors are not adequately prepared to cope with the emotional burden imposed by a dying child. There is little psychological training provided and a very limited hospital support structure for doctors.

Findings indicate that several strategies could be implemented to optimise doctors' coping and improve the quality of care of a dying child and his/her family.

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CHAPTER 1: INTRODUCTION

BACKGROUND

One of the most important and far reaching changes to occur in our society in recent years has been progress in modern medicine and related to it an increase in our ability to postpone the cessation of life. Death was not regarded as the enemy of ancient medicine. It was accepted that it could not be helped. The cultural and religious focus was on finding a meaning for death and on making the passage from life to death as comfortable as possible. Since the writings of Francis Bacon and René Descartes in the 16th and 17th centuries, medicine with its call on science has led to a new awareness of death. Death was declared the enemy (12).

Death, similar to birth, has attained a medical status with all its ramifications. Yet there has been little research about death issues. Why? Perhaps we are in conflict about the place and meaning of death in human life nowadays. Perhaps enchanted by modern technology, which helps to control death and relieve suffering, we tend to view death as "a series of preventable diseases"(12).

Irrespective of views held about death, a life-threatening illness particularly when untimely, evokes huge anxieties that society displaces onto the medical profession. This profession, with a biological and scientific attitude, frequently pursues a frantic search for a cure, rather than reconciliation of issues surrounding separation and loss (8,34,51). The rise of the hospice movement, and recently the development of palliative care as a medical and nursing speciality, hopefully will change this tendency (60).

The dying child in particular creates a very powerful dynamic within the hospital system that is seldom recognized (30,59) and contributes to physicians' distress, who him/herself may be fearful or at least ambivalent about death (28,50).

The idea for this research was prompted by one of my psychiatric consultations at the Red Cross Children's Hospital during my registrarship. I was asked to see a depressed child, hospitalized for over a year, who had suffered from a chronic life-threatening illness. When I attended to him, he was not able to give any account. He was dying. I observed angry nurses in his room, who had put so much effort into his care and who did not achieve the expected results. I wrote a very 'medical' consult about the inappropriateness of antidepressants in this case because of interactions with other medicines he had already been taking, and I joined the silence around the subject of death. The child passed away the next day. Neither the paediatrician nor I attempted any further contact to discuss this patient.

This case made me reflect on the topic of a dying child, medical care and its psychological aspects, as well as the doctor herself/himself. How does a dying child affect the medical professional? What do they value most, the biological improvement or the well-being of the patient as a whole? Whom do they treat, the patient or their own anxieties?

LITERATURE REVIEW

The literature review shows that physicians treating dying children have been rather neglected, as compared with other role players: children themselves and their parents. The available research consists of single case reports, quantitative studies, surveys, and a few qualitative studies.

Studies, over the last thirty years, contain the following themes:

1) INADEQUATE EDUCATION REGARDING END-OF-LIFE

Education about death and dying has been relatively new in medical curricula all over the world. Many concerns have been raised about it since its beginnings in the late sixties and early seventies.

In 1972, Schoenberg and Carr wrote that: "inadequate education in the management of the terminally ill probably represents one of the greatest failures in professional education today". They concluded that: "there is a large discrepancy between what would be seen as ideal training for the health professional in the care of the terminally ill and what is actually the past and the present reality." (Schoenberg and Carr, 1972 in 44)

In 1972, a survey reported by Liston showed that only half of the 83 responding American medical schools had formal programmes dedicated to death and dying, and nearly 90% of these had been in existence for only five years or less (Liston, 1973 in 44)

What were the methods used in teaching the topic? In 1976, Dickinson showed that six schools (6%) of 107 American medical schools had a full-term course, 44 (41%) had a "minicourse", and 42 (36%) provided one or two lectures on the subject. 14 schools (13%) had no formal course on death and dying (Dickinson, 1976 in 44).

In 1983, Berman and Villareal (3) described a seminar held for an entire day and evening away from the hospital for four small groups of six interns, a nurse or social worker, a chief resident and two paediatric faculty members. Illustrative cases were prepared to facilitate discussions of the interns' personal experiences in four areas: the delivery room, intensive care nursery, ward, and emergency room. Interns felt that the opportunity to discuss death and dying early in their training benefited them by gaining an understanding of their own feelings about death. These insights enabled them to cope better with the stress involved in caring for dying children. Other advantages of the seminar included more effective interpersonal communication, the establishment of deeper and more meaningful friendships, and a stronger esprit de corps.

In 1984, Behnke (4) looked at existing teaching about death and dying, and the extent to which it prepares resident physicians to provide confident psychosocial support to dying patients and their families. None of the 10 female residents considered themselves qualified to counsel, in contrast to seven of 16 male residents who did feel qualified to counsel. The gender differences in attitudes toward dying patients were also noticed by Dickinson (19). Men may be less willing to admit inadequacies, since it does not fit the masculine model of physical courage, competitiveness, and toughness as

described by Balswick and Peek (Balswick and Peek, 1971 in 4). Almost all respondents in Benhke's study indicated a need to be involved in death counseling education. 52% of residents stated that training in this area would provide them with more confidence in pre- and post death counselling.

In 1988, a random survey of American schools for medical, nursing, and social work students "revealed no evidence of a consensus on the need for death education for health professionals, no evidence of systematic development of course content or approach, and no evidence of any attempt to integrate training and facilitate collaborative team care in this area." (Dupont and Francoeur, 1988 in 44)

In 1989, Mermann, Gunn, and Dickinson (44) reported on a death and dying course offered at the Yale School of Medicine using patients as teachers. Each student met individually with a patient during the semester and in small groups with the instructor to discuss the interviews, personal reactions, and professional issues while caring for his/her patient-teacher. The authors concluded that the seminar enabled the students to learn the effects of serious illness on patients, the patients' coping strategies used in daily living, characteristics of the caring physician, and skills needed to provide compassionate care.

In 1998, Khaneja and Milrod (32) examined educational needs among paediatricians caring for terminally ill children. They concluded that an educational and emotional support system needed to be implemented into the structure of paediatric residency training programs. They found that paediatricians received inadequate teaching, both in medical school and during postgraduate training. They recommend a systematic, integrated, didactic curriculum on caring for dying children and their families for paediatric residents including hospice or palliative care rotations. Attending paediatricians should be trained as well, so that they can serve as role models for residents. After each paediatric death, the staff involved should discuss the case with a bereavement counselor in order to explore their anxieties and fears surrounding death and dying and to experience a sense of validation in a peer group setting.

The recognition of the importance of medical education about end-of-life (EOL) care in the paediatric setting has been steadily growing. In 2000, Sahler et al. (56) reported on the outcome of the National Consensus Conference on Medical Education for Care Near the End-of-Life in the U.S. The authors emphasize that the ultimate goal of EOL care education is to provide more humane care to the very sick children, enhance bereavement outcomes for their survivors, and develop more confident clinicians. Six principles regarding EOL care in paediatric setting were described. "1) Cognitively and developmentally appropriate communication is most effective. 2) Sharing information with patients helps avoid feelings of isolation and abandonment. 3) The needs of the patient are served when the ethical principles of self-determination and best interests are central to the decision-making process. 4) Minimization of physical and emotional pain and other symptoms require prompt recognition, careful assessment, and comprehensive treatment. 5) Developing partnership with families supports them in their care giving efforts. 6) The personal and professional challenges faced by providers of EOL care deserve to be addressed".

It is stressed that effective teaching about EOL care requires faculty development and "commitment to the value of understanding terminal illness and death as part of the continuum of life, to emphasizing the critical role of medicine in

alleviating pain and suffering, and to acknowledging how emotionally difficult yet professionally satisfying it can be to assist a child and family through this experience”(56). A trainee can gain a richer and broader view than the physiological perspective of the patient’s illness by taking better advantage of the many teachable moments that are already available.

2) PHYSICIANS’ ATTITUDES AND RESPONSES TOWARDS DEATH AND DYING

Any person, be it a caregiver or a patient, who comes in to contact with impending death experiences a broad range of feelings. Elizabeth Kubler- Ross (34) in her pioneering description of responses to dying and death identified the following stages: 1) shock and denial, 2) anger, 3) bargaining, 4) depression, and 5) acceptance. Those who survive a significant loss experience grief reaction and go through bereavement, which according to Bowlby (8) consists of 1) acute despair, 2) yearning and searching for the deceased, 3) disorganization, and 4) reorganization.

Doctors as caregivers, although well defended, are not immune to the process of dying. As a group, they have high levels of fear about death and they may choose a career in medicine in general, or in a particular speciality, as a way of dealing with these fears (Feifel, 1976 in 38, Feifel, 1967 and 1963 in 69). Doctors have a need to master high levels of fear about death by gaining the power to cure, control disease, and save lives. Death anxiety has been found to be associated with age, sex, personality and need for achievement (38).

Livingston and Zimet, in their study of medical students, indicated that the choice of paediatrics as a speciality was correlated with a higher than average score on a ‘death anxiety scale’ (Livingston and Zimmet, 1965 in 9). Many physicians enter paediatrics because “our patients get better”, which is at variance with the subsequent clinical experience (9,38,69).

According to Keniston, medical professionals’ adaptive techniques include a tendency to master anxiety provoking situations rather than escaping or living with them, an orientation toward changing their environment rather than themselves, and an habitual use of intellect as a defence (Keniston , 1967 in 53).

In 1970, Schowalter (58) described his observations during child psychiatry consultations with 10 male house officers concerning 21 dying patients. He identified three psychological stages that paediatricians go through while managing a child with a life-threatening illness: 1) impact, 2) battle, and 3) defeat. These were further elaborated on by Sack et al (53) who conducted a semistructured interview with 36 third-year paediatric residents at four Western university training programmes in 1984.

Impact. Physicians were the first to know the diagnosis. They felt the impact of diagnosing a fatal condition, particularly when they had to communicate the devastating news to the parents. The residents often experienced feelings of inadequacy in being unable to provide parents with the information the parents requested.

Battle. During this stage physicians frequently experienced a pattern of emotions similar to that of the child's parents: denial, guilt and grief, as well as feelings of inadequacy in being unable to cure the child or counsel the parents. They felt like withdrawing from a dying child and his/her family (58) At the same time, residents stressed the increasing skill in their communication and the increased sensitivity to how families adapt to stress over time.

Defeat. Death of a patient was either shocking or expected. During this stage, similar to the Battle phase, doctors often identified with parents of the dying child. Many doctors experienced guilt/blame syndrome, which is one example of the emotional hazards for particularly young doctors who have enormously high expectations of their ability to sustain life (53,55). Death also provides some relief and emotional release. Most house officers found it emotionally easier to inform parents of their child's death than it was initially to tell them about their child's fatal prognosis. A child's death also evoked a sense of defeat (32,53). For the profession that is dedicated to healing and well-being, it implies that doctors have nothing to offer when clinical skills ultimately prove ineffective (44). Professional acculturation in general shapes further attitudes towards death, which is often viewed as the ultimate failure. (32,34,53,55,62,64,67).

Many physicians may have a religious background, which may be at variance with that of the patient and his/her family (47,64). Such a background may also influence doctors' attitudes towards death and may exert an influence on their clinical management of dying patients.

3) PHYSICIANS' INTERACTIONS WITH THE PATIENT AND HIS/HER FAMILY

The death of a child is known to be a stressful experience for physicians, since it contradicts the natural order of things: children are not supposed to die.

According to Sahler et al. (55) the physicians' emotional interactions with dying patients differ according to the child's age and his/her neurological status. Wiener (69) reports that the majority of paediatricians in his survey were of the opinion that children should seldom or never be informed about the nature of their illness. However, they favoured disclosure if the child directly requested such information.

Respondents in Khaneja's study (32) were more likely to discuss issues of diagnosis and prognosis with terminally ill children and children infected with HIV with increasing age of the child, which reflects an appropriate sensitivity to the developmental status of the child and his/her ability to understand the concept of death. There was no clear agreement among the paediatricians with respect to the perceived need to limit emotional involvement with dying children and their families.

Their relationship with the parents generally reflects doctors' attitudes toward the child, but is also affected by the duration of the illness. Sahler et al. (55) identified three general types of intern-parent relationships: 1) active, mutual involvement where the interns offered both emotional as well as medical support to parents; 2) passive noninvolvement where the interns did not meet or talk to any of the parents before the children's death; 3) active avoidance, which occurred in the

case of very hostile and angry parents. Some interns saw the child as part of the ongoing parent-child relationship and understood the role the child played in the family. The interns saw themselves helping not only the child, but also the parents with the adjustment to the eventual final outcome.

Despite the fact that an increasing number of families turn to health care professionals for comfort and support, studies show that doctors do not feel confident and do not have enough knowledge and skills regarding parental counselling (3,53). Many surveys report that a significant percentage of parents express dissatisfaction with the manner the hospital staff handled them (33,52). Most valued by the parents were doctors' availability, providing medical information and grief counselling (26).

Knapp et al. (33) notice that: "Many physicians, unfortunately, are unable to meet the parents' needs because they can not deal with death on the personal level, and/or their training militates against their accepting a shift in responsibility from "healer" to "counsellor-consoler". Thus, an impasse often is reached in which the expectations of parents exceed the service that the physician is able or willing to render. This detracts from the physician's ability to fulfill adequately his role of provider of total care."

Taking into account the above factors, it is of note that many young physicians are left on their own and are vulnerable to developing patterns of interactions that may not serve the patient well. As Wiener (69) put it, " They (doctors) confront a conflict in the care of a dying patient between forces of compassion pressing toward involvement and forces pressing toward avoidance and protection from painful feelings".

STUDY AIM

A study of physicians facing a child suffering from a chronic fatal illness appears to be particularly relevant in the current South African context where, apart from chronic life-threatening illnesses, the epidemic of AIDS puts a substantial emotional pressure on all physicians, both in public and private sectors, in hospitals and in out-patient clinics (45).

The proposed study question:

" You remember one of your patients who suffered and died from a chronic fatal illness; tell me about yourself in this particular case, yourself as a doctor and as a person."

aimed at exploring senior paediatric registrars':

- 1) feelings encountered during management of a child with a fatal illness and his/her family;
- 2) coping skills;
- 3) functioning in the hospital milieu (the impact of a dying child on a doctor's relationship with his/her colleagues and nursing staff);
- 4) the impact of a dying child on a doctor's personal life and his/her value system.

The study aimed at increasing the awareness of the effect of the death of a child on paediatricians' psychological well-being. This may lead to a discussion around the ways of coping with an emotional burden that the growing population of terminally ill children imposes on the medical profession. The results of the study could be used in devising a plan towards improving knowledge about a dying child and the skills necessary in the satisfactory management of patients and their caregivers.

University of Cape Town

CHAPTER 2: METHODOLOGY

RESEARCH DESIGN

This qualitative study was exploratory and descriptive, using in-depth individual interviews with senior paediatric registrars employed by the Red Cross Children's Hospital (RCCH).

The research design was based on the literature of Denzin & Lincoln (16,17) and Marshall & Rossman (40).

SAMPLING

In order to explore doctors' experiences with a dying child the sample of senior paediatric registrars at RCCH was chosen. The hospital employs 30 registrars (9 senior and 21 junior registrars). It is a tertiary institution where the registrars encounter a broad range of chronic fatal illnesses. This hospital is a fairly accessible source with which the Child and Family Unit has had long-established links. In this regard the study was both time and cost effective.

To assure informational adequacy the following factors were taken into account. The senior paediatric registrars, being in their thirties, have already attended to many dying children. The position of a senior registrar provides them with more opportunities to reflect on the work they do. On the other hand, because they are still in the relatively early stages of their career they may remember well their encounters with the subject of death and dying during medical school, internship, and junior registrarship. Being in one's thirties also constitutes a time when at least some of the registrars are married and have their own children which may impact on how they see themselves in relation to the dying children and their parents. Working as a senior registrar implies much less supervision by consultants. For that reason the experiences of the senior paediatric registrars could be representative of medical officers in primary or secondary hospitals.

In order to access the registrars the Director of the School of Child and Adolescent Health, University of Cape Town (UCT), was approached and presented with a study protocol. He consulted with a paediatric oncologist who informed the registrars about the project. The registrars stated they would be willing to participate in the study. The protocol was discussed with 8 registrars (1 female, 7 male registrars). A list of 8 participants with their contact telephone numbers was drawn up during the meeting. The ninth registrar was approached telephonically at the later stage, but did not accept an invitation to participate in the study. The sample of 8 registrars was thought to be adequate for the purpose of the study to reach saturation of data (saturation - finding information that continues to add until no more can be found). The registrars were asked to participate in the study on a voluntary basis, which aimed at ensuring their cooperation and thorough and thoughtful responses to questions.

Having obtained the registrars cooperation, the study protocol was further critiqued and refined at the Research Protocol Meeting in the Department of Psychiatry.

PARTICIPANTS

After the individual and focus group discussion the registrars were asked to give the following personal details: the date of birth, year of graduation, number of years in practice, number of years as a paediatric registrar, marital status, occupation of their spouse (medical or non-medical), and whether they have children. Six out of seven registrars, who attended the focus group, responded.

Age	33 - 43
No of years in practice	7 - 10
No of years of registrarship	3 - 5
Marital status	
• Single	2
• Married	4
Spouse's occupation	
• Medical	2
• Non-medical	2
Children	
• No children	2
• One or more children	4

CONTEXT

RCCH constitutes part of the School of Child and Adolescent Health. This academic structure of the University of Cape Town represents 350 doctors, nurses, therapists, social workers and laboratory scientists who, in partnership with provincial authorities of the Western Cape, provide health care for children in 6 hospitals and several community health centres in and around Cape Town. The registrars rotate through RCCH, Groote Schuur, Mowbray Maternity, Somerset, Conradie and Victoria Hospital. These hospitals treat neonates, children and adolescents from the Sub-Saharan Africa and the whole South Africa. Most patients come from three ethnic/language groups living in the Western Cape: Xhosa, English, and Afrikaans. As state hospitals they provide care for majority of children from low socio-economic strata. HIV infection has been a rapidly growing health care problem. "From 25-40% of the children in these facilities on any given day are HIV infected" (72).

THE RESEARCHER AND HER ROLE

The researcher worked in paediatrics as a medical officer for a year and a half. She has been working in psychiatry since 1995, initially as a medical officer and registrar, and since 1999 in child psychiatry, initially as a senior registrar, and finally, as a consultant since 2001. During the registrarship child psychiatry rotation the researcher was involved in consultation-liaison psychiatry at RCCH. The involvement in this regard has markedly extended since senior registrarship. Part of the current involvement at RCCH is constituted by psycho-social ward rounds. During these meetings the issues of death and dying are frequently raised. Thus, the researcher has a fairly good knowledge of the hospital environment and problems the medical staff have to deal with. The researcher also possesses skills to conduct interviews that may be evocative and emotional, and to contain feelings of the participants, if necessary. The researcher was known to some registrars at RCCH in the capacity of a consultation-liaison psychiatrist.

It was thought that the study interviews, apart from contributing to the broadening of knowledge, could give the doctors an opportunity to 'off-load' the emotional stress in a safe and neutral atmosphere. The study could also contribute toward strengthening relationships between the Child and Family Unit and Red Cross Children's Hospital and increasing the awareness of the role of a consultation-liaison psychiatrist.

Finally, the researcher also hopes to influence changes in a teaching programme concerning issues around death and dying and to create a support structure for doctors.

SETTING

The in-depth individual interviews were conducted with all voluntary participants at their convenience at the Child and Family Unit, because of the quietness of the place and less distractions.

ETHICAL CONSIDERATIONS

Informed written consent was obtained from the participants. Confidentiality was ensured by:

- Not mentioning names of the participants during interviews and in any written text;
- Using symbols instead of names while analysing transcripts;
- Editing text to prevent any recognition of a particular registrar;
- Using services of a reliable transcriber;
- Storing tapes, transcripts, and discs in a safe place.

It was also agreed that should a participant have been in need of any therapeutic intervention, the appropriate steps outside the research frame would have followed.

The research protocol was approved by the University Ethics Committee on 04 May 2000 (REC REF:02/2000).

DATA COLLECTION METHODS

INTERVIEWING

Individual interviews

An initial individual in-depth interview lasting approximately 50 minutes was conducted with eight participants. Each individual interview was audio-taped. The method of qualitative interviewing with the Free Attitude Interview technique (FAI) was predominantly used. FAI implies the interviewer's summarizing, reflecting, stimulating and asking for clarification of the content. Within the framework of the opening question the interviewee has all the freedom to explore his/her own ideas and suggest new topics which may be, according to him/her, of importance to the opinion expressed.

It was difficult to apply this technique particularly in the first interview for two reasons: 1) the interviewee's anxiety and expectations that the researcher would be asking questions, 2) the interviewer's desire to obtain as much information as possible and unintended application of a psychiatric assessment interview style. Having realized that, the interviewing technique was adhered to in all subsequent interviews, although at times with some difficulties since certain registrars quickly elaborated on the initial question and reflecting on it did not produce any further account. Introduction of new questions, based on previous interviews, stimulated further discussion.

Contemporaneous notes were made by the researcher to document the process and context of the interviews. All registrars were very cooperative. There were no difficulties with making an appointment with them for which they arrived on time. When asked about what had motivated them to participate in the study, most of them replied it was loyalty and support for a colleague. Half of them felt that the importance of the study subject warranted their participation. Most registrars had not given much thought to the issues of death and dying for the purpose of the interview. Since they did not know the study question until the time of the interview, they gave a spontaneous account. The rapport was established easily. Some registrars concentrated on the facts and appeared emotionally detached from the content. The topic, however, was pretty evocative to at least three registrars. Two registrars, who used this interview as self-reflection, were amazed by the insights they gained during the interviews. Most registrars appeared sensitive, empathic, humble, modest, and responsible. The researcher has a strong impression that they all were thoroughly honest in providing their accounts.

Focus group

Following the completion of the individual interviews, a follow-up interview was carried out with 7 participants in the form of a focus group. One participant completed his registrarship and emigrated from the country. The focus group lasted an hour and a half. It aimed at discussing issues that had emerged out of the first interview and at clarifying and/or eliciting further information in order to enhance validity of the study. The main themes appearing in the individual interviews were presented and further comments and clarification were obtained. The focus group was videotaped to ensure correct transcription. Contemporaneous notes were also taken.

All the registrars but one arrived on time. Before the interview started they had appeared very relaxed. They were joking and laughing. They appeared to enjoy being together outside RCCH. They did not seem in a mood to talk about death and dying. During the first 30 minutes some of the group members were noisy, exchanging smiles and clearly not wanting to engage at a different level. Such behaviour can be interpreted as a defence against the evocative content of the group discussion. The situation changed with an arrival of the last registrar. The group became more serious and concentrated on the topic. One registrar, who gave a particularly rich input during the individual interview, continuously from the beginning to the end, tried to devalue the sense of the discussion. The group went along with him for the first twenty minutes and strongly opposed his comments later on.

The discussion was very heated at times with many doctors talking at the same time, which unfortunately impacted on the quality of transcription.

DATA ANALYSIS STRATEGIES

Data analysis strategies outlined by Dey (18), Miles & Huberman (46) as well as Mason (41) were used.

MANAGING DATA

The individual audio-taped interviews were transcribed by a typist. Each interviewee was assigned a letter in random order instead of a name. Because the registrars' names were not mentioned during interviews, the typist was not aware of the doctors' identity. Transcripts were read and checked up by the researcher in order to ensure their accuracy. Eight transcripts were obtained. Each of them consisted of 15 to 20 pages. Each transcript was filed separately in one folder together with consent forms signed by the registrars at the beginning of the individual interview and the notes made during the interviews.

The video-taped focus group was transcribed by the researcher to ensure confidentiality. The same symbols were assigned to the registrars. The sound on the videotape was, unfortunately, poorly recorded and the transcript had to be at times reconstructed using notes made during the group. The videotape was checked by the researcher again two weeks after the initial transcript had been completed. The transcript made up 20 pages. It was filed separately in the folder with individual interview transcripts and additional notes. All transcripts were also saved on floppy disks and stored separately.

READING AND ANNOTATING

After each individual interview the transcript was read in an 'interactive' way with a set of questions to ask the data, like: who, what, why, when, and where in the following areas: settings, definitions, processes, activities, events, strategies, and relationships. The researcher's ideas and impressions were annotated and compared against the previous individual interviews. Some ideas were mapped not only within, but also across transcripts.

CATEGORIZING DATA

Creating categories.

The transcripts were read again and coded. Selected quotes were assigned to a specific concept (code), which was jotted down on the margins of the transcripts. The process was based on inferences from the data, initial ideas confirmed by the data, theoretical background, intuition and previous knowledge.

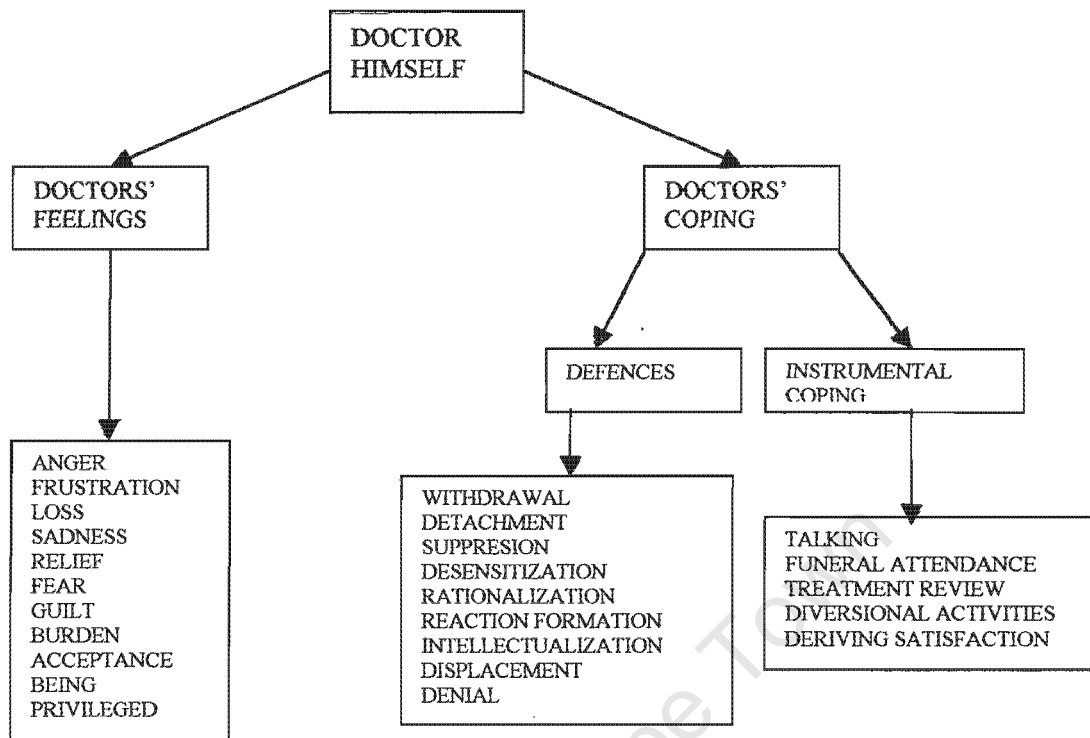
Thus, coding was conducted in a literal, interpretative and reflexive way. E.g., " How could they make that decision that they couldn't do anything further for this child..." - was coded as denial and anger.

Codes were further grouped into categories and subcategories. The subcategories and categories were continuously compared with others across all the available transcripts. Two lists emerged.

E.g.,

CATEGORIES	SUBCATEGORIES
Doctor him/herself Illness Support Teaching Culture Patient Patient's parents Staff interactions Doctor's family	Doctors feelings Doctor's coping Doctor's professional growth Doctor's emotional growth Quality of life End-of-life decisions Acute death HIV/AIDS Bonding with patient Patients' responses to doctor Parental expectations Bereaved parents Funerals Language and interpreters Cultural beliefs Communication among the staff Expression of feelings among the staff

The lists were further refined and mapped. E.g.,



The process of creating categories was discussed with the supervisor who conducted random analysis and categorization. Any differences were discussed further.

Assigning categories

Having established lists of categories and subcategories, the sentences and/or whole paragraphs were copied, transferred from its original context, and filed under the assigned categories. The symbol of a particular registrar together with the page number of a specific sentence or paragraph were retained in order to be able to locate the original text, double check the context and appropriateness/accuracy of a category assignment. "Microsoft Word 2000" was used for this process. Specifically designed computer software for qualitative research analysis was, unfortunately, not used.

The text was further edited. Long pauses and "uhhms" were erased. Incomplete sentences were edited in order to convey the context and meaning.

Splitting and splicing

The subsequent analysis consisted of 'recontextualization' of the data, where the data were organized and analyzed in terms of developed categories rather than in terms of its original context.

Some categories were modified. All of them were split into subcategories in such a way that they made sense conceptually, they were empirically relevant, and they were useful practically and analytically. Some paragraphs illustrated more than one subcategory.

They were analyzed again and assigned to the theme that they were more specific of. E.g., doctors' feelings of sadness or anger were expressed in both any chronic illness and HIV/AIDS. However, because the background of these feelings had

been distinctly different they were assigned to “Doctors’ feelings” subcategory, but under two separate categories: 1) Doctors themselves, and 2) Illness.

The relationships and boundaries between categories and subcategories were reevaluated. Overlaps were clarified. The search for an explanation of incongruities or surprising findings was conducted using the original transcripts. The findings were discussed with the supervisor. E.g., hardly any registrar openly admitted feelings of personal failure on the patient’s death, contrary to the literature. The deeper analysis of the text showed, however, that many registrars felt guilty when not providing active treatment or when making mistakes, with a tacit message of having failed professionally.

LINKING DATA

The process of categorization did not take into account substantive relations between the codes. Linking data aimed at finding out how things interacted. The links were either explanatory or causal.

CONNECTING CATEGORIES

The categories and subcategories were further compared and looked at for evidence of connection between them. Where two categories were assigned to the same text, the data was regarded as confirming a connection. The linked data were included in the process of making connections. Associating and linking was performed with the help of maps and matrices. Each subsection of results will begin with a finally refined map illustrating such connections.

RELIABILITY AND VALIDITY

Qualitative research defines reliability in terms of dependability of data. This implies that the findings of a study should be consistent if replicated with the same subjects or in a similar context using the same methods. The following steps were taken to enhance reliability:

1. The registrars participated in the study on a voluntary basis. Confidentiality was ensured at all levels. This is thought to contribute to a thorough, honest and reliable account obtained during interviews.
2. The researcher possesses well-developed skills helping to interpret not only the content of the interviews, but also non-verbal responses and the process of the study.
3. Both the individual interviews and the focus group were recorded to ensure accurate transcripts instead of relying on the researcher’s notes and recall alone.
4. The coding procedure was conducted by the researcher on two separate occasions and the results were compared.
5. The supervisor independently coded and categorized randomly selected pages from several interviews. This was compared with the researcher’s results. Discrepancies were discussed.
6. The above detailed description of methodology has been provided to assist future researchers with replication of this study.
7. The track of coding strategies was saved and stored for future references and reflection.

Validity is defined in qualitative research in terms of credibility (internal validity) and transferability (external validity).

Credibility refers to demonstration that the inquiry was conducted in such a way as to ensure that the subject was accurately identified and described. Validity of qualitative data requires sufficient time to be spent with participants in order for themes and patterns to recur and be verified. To enhance credibility the following steps were taken.

- 1) A technique of member checking, whereby the researcher checks with participants whether s/he has correctly understood them, was used in order to reduce misrepresentation.
- 2) Triangulation. The term refers to the combination of methods in the study of the same object or event in attempt to depict more accurately the phenomenon being studied. Methodological triangulation was employed, whereby two data collection techniques were used, individual interviews and the focus group. Data that coincided was verified which improved its validity. Investigator triangulation was partially achieved by the supervisor's active involvement. Data triangulation was not employed. Other sources of data were not sought. The literature was consulted on completion of analysis in order to identify common themes and validate the information obtained.

Transferability refers to empirical and theoretical generalization. The first one is based on logic whereby generalizations from an analysis from one empirical population are statistically representative of the wider population. In these terms this study is not generalizable. From a theoretical point of view this study could be generalizable for the following reasons.

- 1) " The information derived from *any participant* is valid because that account is a product (albeit complex) of the social domain. "(27,p.15);
- 2) It is possible that the most analyzed processes work in the same way across all health care professionals since they are universal, like grief responses, coping, bonding with the patient, cultural differences, professional growth;
- 3) The rigor of analysis built up plausible explanations, which could be easily tested out among other professionals dealing with dying children;
- 4) Most categories reached saturation.

RESEARCHER'S BIAS

The qualitative study is never objective since a researcher's subjectivity is an integral part of interactive processes taking place during the study. However, the researcher is fully aware of the bias, which was taken into account while conducting and interpreting the study.

1. The researcher's medical training could have led to significant identification with the participants.
2. The researcher's own limited teaching about death and dying during medical school.
3. The researcher's work in paediatrics, encountering dying patients there and holding her views about it, could have caused stronger identification with certain aspects mentioned by the registrars at the expense of others.
4. The current involvement at RCCH and observing responses of the nursing staff towards dying children could have contributed to overemphasizing certain attitudes, which may not be so important in the doctors' case.

5. The researcher's psychiatric qualifications could have had an impact on the way data was collected and interpreted.
6. Conducting interviews in English, which is the researcher's second language, could have led to the omission of some language nuances.

MANAGING TIME AND RESOURCES

A meeting with the Head of the Department of Paediatrics, UCT, and an introduction of the idea to the registrars took place at the beginning of March 2000. Recruitment of participants was completed in the middle of May 2000. Interviews with individual registrars started in June and ended in October 2000, with completion of an early analysis during that time. The focus group took place at the beginning of February 2001. The final analysis and report were completed in June 2002. Feedback to the Department of Paediatrics and Psychiatry as well as submission of articles to relevant journals for publication should be completed through the year 2003.

Cost: The study required a tape recorder, tapes, filing systems, stationery, floppy discs, telephones, tape transcription services and computer access. Financial support was negotiated with the Department of Psychiatry and Mental Health, at the University of Cape Town. The grant of R2000 was received in December 2001.

IMPLEMENTATION.

Since the outcome of the study will be of interest not only to pediatricians, but also to other health professionals caring for a dying child, the results will be presented during one of Wednesday academic meetings at the Red Cross Children's Hospital. The preliminary results of the study have already been presented during the Research Day at RCCH in October 2001. A short article concerning the HIV/AIDS aspect of the study was published in MCH NEWS in December 2001.

The report will also be presented to the Teaching Committee in the Department of Psychiatry and Mental Health, UCT, for discussion concerning curriculum changes around teaching regarding death and dying.

CHAPTER 3: RESULTS

INTRODUCTION

The study aimed at exploring the registrars' experiences with children suffering from a chronic fatal illness. Many registrars, however, associated the question with the subject of death, and were initially referring to a broad spectrum of illnesses which cause death. The first section is dedicated to any fatal illness and the problems connected with it. The subsequent sections present results related to the chronic fatal illness only.

The results are included in the following sections:

1. DOCTORS' ATTITUDES TOWARDS A FATAL ILLNESS
2. DOCTORS' TRAINING
3. DOCTORS' INTERACTIONS WITH A DYING CHILD
4. DOCTORS' INTERACTIONS WITH PARENTS
5. DOCTORS' PERSONAL RESPONSES WHILE FACING A DYING CHILD
6. EMOTIONAL SUPPORT FOR DOCTORS

The results in each section are preceded by a map of links and connections between major categories. The map constitutes an overview of the content included in the section. Shapes and colours used in these maps do not have any systematic meaning. Since subjects raised in every section are very distinct, the results are followed immediately by discussion, conclusion, and recommendations specific to that subject. The overall conclusions resulting from the above sections are presented in the chapter 'Final Conclusions', followed by 'Summary of Recommendations'.

In the 'Results' subsection, bold print represents the researcher's comments, while bullets introduce the registrars' quotations, with each paragraph representing a separate statement. The symbols of registrars' names were omitted to ensure confidentiality.

SECTION I

DOCTORS' ATTITUDES TOWARDS A FATAL ILLNESS

Figure 1: Illness

'ACUTE' DEATH

- Results
- Discussion
- Conclusion
- Suggestions to explore

HIV/AIDS

- Results
- Discussion
- Conclusion
- Suggestions to explore

QUALITY OF LIFE AND END-OF-LIFE DECISIONS

- Results
- Discussion
- Conclusion
- Suggestions to explore

This study was not designed to explore the doctors' experiences with a child dying of an acute illness or AIDS specifically. However, many registrars often made references to the above, which because of their significance were grouped in two separate subcategories: The 'Acute' Death and HIV/AIDS. These topics are regarded as the introduction and background to the essential topic of chronic fatal illness and for that reason will be discussed briefly. This chapter also includes some questions around the quality of life and ethical dilemmas surrounding end-of-life decisions.

Figure 1 illustrates the following points:

- The registrars encounter death in three types of illnesses: acute, chronic and AIDS related illnesses;
- End-of-life decisions are integral part of patient management.;
- The awareness of the patients' quality of life may impact on the end-of-life decisions.

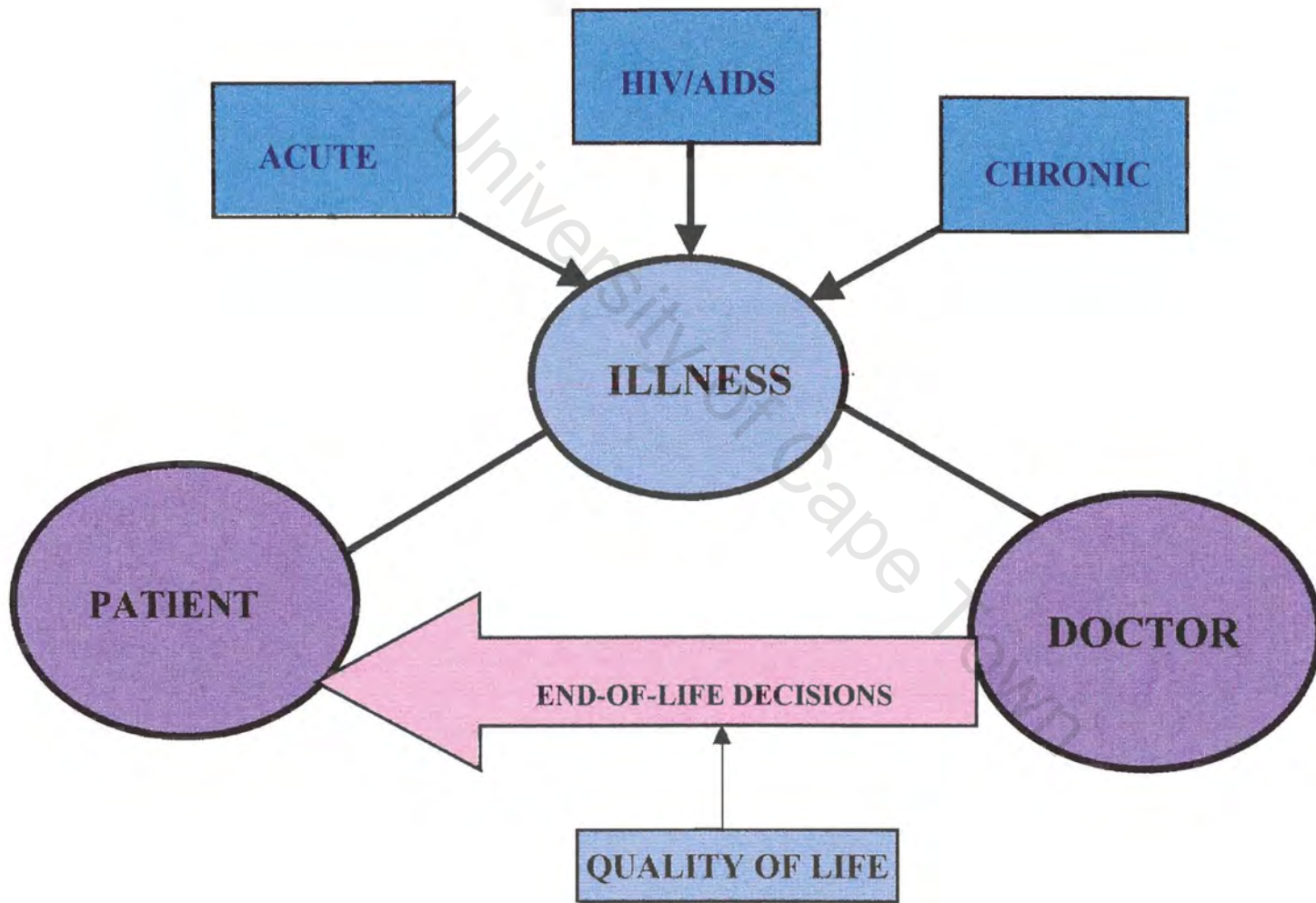


Fig 1: ILLNESS

'ACUTE' DEATH

RESULTS

The registrars emphasized the different quality of a relationship with an acutely ill child and his/her family. They meet the patient in an emergency situation, often with hardly any knowledge of his/her previous medical history.

- They come in and they die, and it's very traumatic. They disappear, and I normally don't see them again. They go to a social worker. So to tell you an honest truth, it's not particularly pleasant in a sense that there is no intimacy. You don't know them. You don't know the issues. You don't know where they are in the child's disease. You simply have to try resuscitation or nothing at all, and then inform the mother who cries. And you don't have a social worker backup. You're often in a very busy environment.
- In the acute case the expectations are even higher. In a chronic child congenital defects have been there from birth. Parents don't expect miracles.

The 'acute' death represents a medical loss, not followed by any specific feelings that would otherwise be experienced in the case of a chronically ill child. It takes its toll, however, if many such deaths occur in a short span of time.

- What you feel mostly is the loss from a medical point of view that you couldn't save this child. But you don't know this child at all. You sometimes don't even see the parents. So your feelings are much more clinical. Your emotions are evoked because of the work, but not so much because of the whole child.
- If I work in med-reg and a patient comes in here, who's not breathing at all, I resuscitate him, which is an unsuccessful resuscitation. You have to speak to parents you've never met before. You go through a protocol. It's like a set up protocol. The textbook describes it to you. Have empathy, be supportive, stuff like that. But if you asked me whether my heart is aching or whether I'm emotional, then I can also say, not at all. This is part of the job; it's not my fault. One of the things a doctor always wants to know is whether any intervention from his side could have made a difference. Were you at fault? And as long as you can satisfactorily say that after I did everything in my power to help this child, it's out of my hands, then I feel relieved about that. It's more difficult where you've known the child and you've talked to him frequently, you've become friends with him.
- The 'acute' death (as opposite to the 'chronic' death) can be more draining on a short-term basis. You can have a terrible night in the unit where you can lose three or four children, and you can feel absolutely like wrecked the next morning both physically and emotionally. You just don't have anything left. You had to go through that

thing with the parents, with people you don't know at all, several times. I always find that really hard after I've done everything I could possibly think of. Then I think: "What didn't I do properly?"

The doctors may resuscitate the patient. The experience is very rewarding if s/he succeeds. If the doctor fails he/she has to deal with a great amount of parental distress, anger or other unpredictable feelings.

- Those that are in a decent medical state and get to me alive I can resuscitate. It's very rewarding.
- In the responses that you sometimes get from 'acute' death, the parents can still be very angry and very vicious or take it out on you as a person, and say: "You killed my child".
- (Cot deaths) those are very difficult, particularly when a mother arrives, she runs into your ward with a cold blue baby, and you immediately can feel her anger. If the doctor hadn't discharged her five days ago, her baby would still be here well in hospital.

The registrars have different ways of responding to grieving parents in a busy emergency setting, from active listening, sedating a parent to delegating some counselling to other professionals, e.g., social workers or nurses.

- In the circumstances of a child dying acutely, (when) the child's just died, the last thing they (parents) want to hear is the long physiological explanations of diabetes and syphilis and why the child has become dehydrated. They're just not gonna hear anything really. The words are comforting, hopefully, not that they're going to make any difference really. One thing I'm not a great believer in is that lots of people run off and get Valium out of the schedule-five cupboard and throw Valium down anyone's throat. I think that's bad, unless someone's threatening to throw themselves out of a window or something, but I've never had that experience. If people want to cry for an hour or two hours or they get up and say: "I'm going home, I don't want to hear about this, I'm going" - that's their prerogative. I feel quite well. I don't have a problem with people expressing themselves how they want to express it, and I'm really there. If they want to hit me, I'm not all that keen, but that's also their prerogative.
- You arrange for the social worker to come and assist you, because they're very good at what they do. They have time to do that kind of thing. I always find the nursing staff very good, particularly if the patient is Xhosa. You need someone to translate sometimes for you, and in that terrible time of grief the last thing they (patients' families) want to do is struggling through your English. They want to hear it in their own language. I think there should always be someone with them, and it's either me or I ask the nursing staff or the social worker. The people often want to be alone after a while. They just want to sit quietly and you know I always say to them: "You're always more than welcome to come and ask me at any time anything about the event".

The doctors also have to deal with their own sense of inadequacy as therapists. No amount of immediate counselling is going to lessen the pain of losing a child.

- Having just experienced of personal death, a family death, I don't think anyone is going to meet your needs, any medical professional. Then being a bit softer and gentler is certainly going to help, but there's nothing that can really fulfill your needs in the acute unprepared loss of life. That's a very traumatic experience.

Any counselling in such a situation is very difficult and frustrating for the registrar because of lack of previous involvement with the parents, the sudden nature of death, the tragic dimension of the child's death, and frequently cultural and language differences.

- You tell them what you think happened. And then, there is normally a lot of crying and disbelief, or depending on where they are, and you fill up some forms, and you ask them whether they're all right. You must spend 20 min at the most with them, and then they disappear. That's very difficult.
- Very often a lot of kids dying in our casualty are Xhosa patients, because HIV is prevalent in that group. So very often language is a problem.

The environmental factors like time constraints, paperwork and other patients to attend to add to the tension and unpleasantness of the situation.

- When dying in the casualty you're not gonna find empathy. That's the wrong place to look for empathy. It's just too busy in a developing world like ours. There's too many issues.
- You have another three patients waiting. That's not very taxing on me. Counselling - it's a hassle, in a sense I'm doing an incomplete job through circumstances. You can't begin to scratch the surface of that woman's needs.
- There's a lot of paper work. You're gonna be sitting over 10-15 minutes, and then you're always going to get called back because you've forgotten something. They're very complicated forms to fill out. These are issues when you're busy, that's the issues that go through your mind. It's a hassle and that's very unfair on somebody who's just lost their child.
- In an ideal acute setting, I would have a social worker on site, preferably who can speak Xhosa, I'd have another doctor to take over the rest of the loads that you could actually settle down and do everything properly, and fill out the forms. You could also speak longer to the parents with the interpreter.

Although the hospital does not provide any specific support structure for parents whose children passed away after a short illness, a follow-up is usually offered. Sadly, only a small percentage of parents come back. Some of them embark on legal action.

- In an acute setting (support structure for parents, follow-up) - it's not very well set up at all. It must be horrendous to go through that.
- Some parents do come back, and I certainly invite them back. But, again it's unrewarding. I certainly try to get them back to see a social worker, and some do. But many mothers are indigent and they can't get back. It's just too expensive and far. But some parents, I must say, about 30% of parents must come back.
- The ones who take you up on the offer are usually contacting you with a lawyer to say: "Well, you know, we're unhappy with the way our child was dealt with", or something like that. I mean, which also fortunately in South Africa, it's an infrequent thing, and I haven't had to deal with it that much, but they seldom come back to you for answers or to talk.

DISCUSSION

Although the study question pertained to a chronic fatal illness and the question was understood properly, most registrars seemed to associate this type of illness with the topic of death and dying. They frequently referred to any condition that could have a fatal outcome. This itself indicates the importance of raising the subject of death in general. It may also suggest that talking about a chronic fatal illness is more evocative and reflecting on an acute death appeared safer and provided some emotional refuge.

The discussion of the 'acute' illness and 'acute' death centred on the registrars' medical function, which implies very active treatment. Since this is what they have been trained for, they tend to feel comfortable in this role. A short contact with a patient and his/her parents leads to purely 'clinical' feelings. The feelings are more related to the appropriateness and success of resuscitation or any other relevant management than to those resulting from a close long-term relationship with the patient and his/her parents, which is so characteristic of chronic illness. The relationship with the patients and their parents is almost non-existent in the case of an acutely ill child who died. It is a source of frustration for the registrars for several reasons:

1. The doctors have very limited knowledge of the child;
2. They do not have an opportunity to bond with the parents;
3. They have a limited amount of time they can spend with the parents because of paperwork and workload, and frequently are not able to provide adequate counselling;
4. The tragedy of sudden death evokes powerful responses of shock and anger in parents who tend to project these feelings onto doctors, which are not always realized by them.

CONCLUSION

In the case of the 'acute' death of a child, which constitutes a sudden and extremely tragic event, the registrars frequently faced distraught and very emotional parents, with whom they had not developed any relationship before. Such a situation, particularly when coupled with paperwork and other emergencies, is not conducive to providing post death counselling. It seems that these circumstances, more than the death itself, are the major source of stress and uneasiness for the doctor who may become overwhelmed in the case of multiple deaths.

SUGGESTIONS TO EXPLORE

It is suggested that the stressful nature of 'acute' deaths is recognized and acknowledged by the consultants in daily rounds and discussed with the registrars, if necessary.

Since counselling for the parents is extremely difficult in such situation, it is important to provide and ensure follow-up for them (43).

HIV/AIDS.

RESULTS

One of the registrars pointed out that AIDS "is a whole new chapter in the book of dying, and it's not an easy chapter to deal with". The discussion centred on the nature of the illness, the number of patients, their care, counselling, parental attitudes, and doctors' feelings.

THE NATURE OF THE ILLNESS

Most registrars discussed certain aspects of HIV/AIDS since it represents a type of chronic fatal illness. It differs from other chronic illnesses in terms of the amount of attached blame and stigma.

- The difference between HIV and other diseases is that there's so much other overlays with HIV that you're not just talking about the disease. There's usually a lot of blame and social stigma and all the rest that comes with it, which colours the thing completely differently to a disease that the child was born with or might have picked up, like leukemia or a lymphoma that's been found later on.

THE NUMBER OF PATIENTS

Although none of the registrars provided any statistics regarding patients suffering from AIDS, they all agreed that the HIV/AIDS epidemic is huge.

- Many of the deaths that paediatricians have to deal with would be HIV deaths. There are tons of them, tons, tons of them, e.g., last night I admitted two children with HIV who were very sick. One will probably die today. There were two that came today.
- The HIV epidemic is unique. It's huge. The patients are dying in vast numbers and the doctors are being exposed to unnecessary death every day. You can accept the fact that the occasional child is going to get a bizarre, strange condition, it happens, but HIV - there's just too much of it and it's avoidable.

PATIENTS AND THEIR PARENTS' CARE

This topic evoked significant feelings of frustration among doctors. They emphasized that in the current economic climate they cannot afford to provide the best possible care for the patients, in both medical and psychological terms. There are simply too many patients, too few doctors, and too little financial resources to be able to manage this pandemic appropriately.

- In a country, where HIV is absolutely rife and decisions have to be made about these children, we can't afford to keep them all alive by ventilating them and providing the best care available, because we can't afford it.
- You count it up when you do a ward round. You count 3 out of every 5 patients in a high care at least. When I worked in a general ward 30% to 40% of patients were suffering from AIDS, and they're often the sicker patients obviously. They are the ones who take most of the time, and what it often makes things worse, you can't do much.
- In those circumstances, you have a poor relationship with a lot of the parents because a lot of the kids come in when they're acutely sick and they're dead, before you've even got to know the parents.
- With HIV you're not gonna win the battle. Let them go comfortably, not to flog a dead horse.

The registrars stressed the lack of continuity of care, which means that the patients are seen by many doctors who do not develop a long-term relationship with them. Such a situation leaves the patient and his/her parents alone in their suffering.

- What also needs to happen is that there is some decent continuity of care for these children. The children end up in one hospital and the next hospital, under different doctors. There's just not enough resources for a doctor to look after thirty patients with HIV. It's a chronic disease. It's like chronically ill patients. It's like asthma; it's like cystic fibrosis. They should be getting continuity of care under a person, and often they're not.

Despite many frustrations, children with AIDS related illnesses are mostly provided with high quality treatment. Decisions about non-resuscitation have to be made on a daily basis.

- They get a very high level of care compared with other hospitals. At the bottom of Africa we start feeling the impact of epidemic.
- We don't have rigid rules the way some other places do. Although majority won't get to the ICU, they will still get high quality care, and it is often on a personal basis. We would discuss it, which way we approach the question and whether we contemplate the surgery.
- It is a matter of rationalizing. In the Eastern Cape the fact is they are sending children to die – it is not neglect. It is actually quite good.
- No child is thrown into a corner with HIV. If the child is suffering, breathing hard, more infusions are started or, even if it is decided – the end and turn off- you often try to take them out of a high care, put them in a single cubicle, so there is some sort of privacy with the mom.
- I think we are good at palliation. That kind of mind set is only reasonable because of the situation.
- It happens more and more often that you have to tell people the night before which children should or should not be resuscitated. If you've got a dying HIV at the back, you should tell them before the time that, if anything happens, the child does not get resuscitated. You make that decision before you go home. You come back and they're not around.

One of the registrars talked about some neglect of children with AIDS.

- I've seen cases where we had a child, a pre-terminal one, where people don't do the ward round and they write up that this child is not for resuscitation. At ten o'clock they see the child, and the child was dead and people say: "There's another one". There's demand for space that's available. "Let's get this child out of the ward".

COUNSELLING

Most doctors are familiar with techniques of HIV counselling. They find it very difficult since breaking bad news means at least a double tragedy, for the mother and her child. The doctors realise the need for ongoing counselling of parents.

- A lot of death now with younger kids is from HIV, so you always need to deal with the mother's anxiety, and she knows that she's going to go the similar fate. It's often dealing with so many medical problems as well.
- The parent, as soon as s/he's got HIV or has got a child with HIV, needs to be aware that the potential for death is there. I think the counselling is going on. It doesn't make the death any easier but there needs to be that.
- Counselling with HIV (is very difficult), especially when the children have tested positive, and you have to go back and tell the parents: "Not only is your child positive, but you're probably positive too". That's very difficult. That comes with experience as well. I've done that many times. That's difficult.

PARENTAL ATTITUDES

The doctors describe several groups of parents, those who are aware of their HIV status, those who deny it, and those who learn about it in the hospital. Most parents come from communities where AIDS sufferers are highly stigmatised, with very little financial resources. Some of those who deny the diagnosis refuse consent for their child to be tested which creates additional problems and dilemmas in the ward.

- Parents come at night. They can't get home. They don't want the kids at home. The children come to lie on drips in cold inhospitable places. Because the hospital is here they (parents) come seeking help and can't get home. They don't have money. They're mugged. They'd be killed at home. It's not just that the hospital wants to keep them there. It's also the structural thing in society.
- Initially we didn't really suspect HIV/AIDS. But as time went on and we got more results back it became clear that this child could have HIV. We hadn't at that point tested the child. We then decided we must get consent, but blood had been taken with a view to testing and at the time the parents weren't there. They then came in and refused consent for that child to be tested. But the blood had actually been sent already and that was sort of the beginning of a whole lot of issues that just snowballed in the management of the child. The parents never really regained the trust of the medical staff. They didn't want to (be informed about a diagnosis), they refused to be informed. They basically said: "You can't tell us. We don't want to know". They weren't receptive to late counselling about the implications for their sick baby who was clearly dying. Perhaps they understood the implications, but they didn't want to face it. That was very difficult.

- I was initially involved in the early phases. Then I think our action was actually to withdraw quite substantially from them, which was perhaps quite a natural, but quite a negative thing to do in some ways. They seemed to foresee that. They felt that their baby wasn't doing well. There wasn't any evidence for that, but I think the staff withdrew from them because of the anger. They would come in and complain of things that's been done. It came down to strong feelings of anger again, because we thought we were treating their baby as best we could and they weren't really able to come along with us.

DOCTORS' FEELINGS

Although AIDS is a chronic illness, it evokes very specific feelings among the doctors on top of all other feelings mentioned in relation to any chronic illness. The registrars felt that the number of patients and current treatment policies led to doctors' traumatization. Many of them experienced an overwhelming sense of sadness and despair when faced with a single HIV positive mother from a low socio-economic group, who is ill herself, unemployed, stigmatised by the community, and who has to deal not only with her own loss of health, but also with the upcoming death of her own child. The registrars felt angry with those who spread the virus. They struggled with their own hopelessness, knowing how little they could offer, and helplessness while watching a child gasp. Some tried to detach themselves and treat their patients rather as a group than separate individuals. They questioned themselves: "What am I treating in this country?". They experienced real fear of acquiring the infection while drawing blood or performing invasive procedures.

Traumatization

- Another doctor was quite traumatized by saying that they had to put them (children) in the side cubicle. They were very sick and terminal. They're here every day.

Despair, sadness & guilt

- You feel despair because of this huge problem, which is only just starting to get worse. You feel despair for the mother. She's got it. She's probably innocent in a party. Often has such a poor insight into it. They're also indigent. They're from such a poor background. They're just abused women in whatever way. Financially, they'll never have a job. They always bring in these sick kids to hospital. It's been such a futile endeavour. It's such a pathetic illness. So it's a lot of sadness about the illness itself. And then depending on the individuals it varies how sad you feel.
- You become despondent. You think: "what am I treating in this country? What's happening to the country?" As for the disease where is this thing going to end? I feel despondent for the mothers. They in the corner and they'll not be able to find their way out.

- It's a hard thing to watch a child gasp and not be able to do anything about it. So, for the juniors who work in the general wards, maybe the first time they're in that situation, to make that decision is extremely hard on them. And then they still go on for the rest of the night.
- You sit there and the child just demises. You have the situation where that mother's also ill and there's physically nothing you can do. You don't have access to Anti-retro-virals. There's no cure, and then you start apologising for you're telling them: " Maybe in five years, maybe in ten years", trying to be positive.

Fear

- Part of you wants to do tests and drip them. I've always been scared of pricking myself. I keep telling the staff and me: "Investigate minimally, try to use fewer things as possible, as little risk as possible, because it's dangerous".

Anger

- There's also a little bit of anger at the parents. This is a personal thing. It may not come from other doctors. "Why the hell did they get HIV? It's avoidable. Wear a condom". Particularly when dad arrives, maybe it's terribly sick and maybe it's a terribly sexist thing, but they're the guys bringing an end to the relationship. They come waltzing in and you kind of think: "You're the bugger; you are the one who killed this child". It probably does affect the way you discuss things with them and put things across. You're a little bit angry with them. They could have prevented this.

Hopelessness

- With the oncology patients I'd approach them with a lot of hope mainly, and always try and instil as much hope for the parents as possible, because in children in oncology there is a hope. That's the kind of feeling you try and transmit to the parents and although you know that chemotherapy and radiotherapy is gonna make the child very, very sick you can support the child through that. Hopefully, in the end the child will be cured. That's very different to HIV.

Desensitisation

- There is so many children like that. It desensitises us to a certain extent. 10 years ago we used to have one death a month. We used to talk about it. Now we have one death every few days. You can see...they (junior registrars) have a death at night. They take it much harder than we do. We were told to handle it. That's it. You get hardened from this.
- You harden to the fact that someone is dying, but part of me will deal with it because the death is a given.
- You provide them with the most dignifying death but it is still terrible to watch these children dying. To have a ward with 20 – 30% HIV patients and we're losing 2 – 3 a week. It must be demoralizing. You bring them in to try a little bit of magic. The magic doesn't work. You withdraw. They are gone.

Detachment

- There's nobody around children with HIV who are in their late stages of being ill. It's such a terrible lonely experience for them. In their situation it's almost too much. You feel that you just can't tell. It's very difficult to go beyond the medical treatment with that child, particularly the small ones because they're just so alone, and it's overwhelming. There are lots of those patients. You're dealing with many of those patients.
- Yet the implications for those families are very enormous and it's difficult. There are issues of confidentiality. There are issues of trust. It's so difficult in those children to go beyond quite a basic level of medical care, where in this family there was the opportunity to delve into much more of a relationship.
- I've had predominantly patients with chronic infectious diseases such as HIV babies who come in, but I can remember them as a group I don't remember them as individuals.
- As a group they all come in as very, generally speaking, malnourished wasted babies with several different secondary infections, and often when they arrive they actually look like they're about to die that moment. Then you resuscitate them and then they maybe even go home on that admission. Then they come back for three or four admissions more and then eventually they just stay in hospital longer and longer and longer and die. I haven't formed any strong attachments with them.

DISCUSSION

None of the registrars chose a patient with HIV/AIDS for a discussion of his/her experiences. This illness appeared to be particularly emotionally evocative and it was used only in terms of comparison with other chronic fatal illnesses. The registrars tended to place HIV/AIDS between acute and chronic fatal illness.

What connects AIDS with acute illness is:

1. The fact that children die of acute illness in the process of AIDS within a relatively short span of time;
2. A lack of or very short-term relationship with the patient and his/her parents, which is determined by the unique factors described below.

Meyers (45) points out that paediatric HIV infection shares many of the characteristics of other chronic illnesses. He mentions duration, severity of illness, functional impact, and need for ongoing health services. He also pays attention to other aspects, like stigma, altered social experiences, and the heightened potential for secondary psychosocial dysfunction of the child and family, which registrars seem to confirm.

According to the registrars, features unique to AIDS, which differentiate it from other chronic fatal illnesses, are as follows:

1. The disproportionately huge number of patients dying of AIDS;
2. The illness usually involves the child and the parents at the same time, implying a massive amount of counselling required;
3. The stigma and the judgments it evokes even in medical professionals;
4. The lack of continuity of care and ongoing counselling, which usually happens with other chronic illnesses;
5. The registrars feelings of failure, hopelessness, and despair about not being able to provide adequate treatment;
6. Fear of getting infected with the virus.

What transpired in this study and may be unique to the South African context are problems with health care provision and feelings of despair and hopelessness among the doctors. It is these unique features compounded with ethical dilemmas and workload that make the doctors 'harden' or detach from the patient and the patient's parents. Detachment may be a form of a defence against self-traumatization, since the number of deaths may exceed the doctors' capacity to process them.

The topic of death from HIV/AIDS maybe particularly evocative for the following reasons:

- Doctors are confronted with death on a very regular basis, for which they have not been trained and emotionally prepared;
- Doctors' ability to treat is undermined by unavailability of resources;
- They have to deal both with a dying child and his/her dying mother or parents;
- The cultural differences between the doctors and the patients further increase the feeling of hopelessness, helplessness and failure.

Unfortunately, the available literature does not seem to pay attention to these specific aspects of HIV/AIDS (2).

CONCLUSION

Very little attention has been dedicated to the impact of AIDS epidemic on the medical profession. It seems that the doctors do not develop a close relationship with the patient suffering from AIDS for several reasons:

- Lack of continuity of care;
- Unavailability of active treatment that may evoke feelings of failure on the doctor's side;
- Cultural differences, ethical dilemmas, and work load;
- Defence against their own traumatization.

Dealing with a huge number of dying children makes the doctor, understandably, 'harden' or detach from the patient and the patients' parents. This may influence the quality of the patient's care, both the physical and particularly the psychological aspect of it. There is virtually no support or platform where the doctors could express their feelings in this respect.

SUGGESTIONS TO EXPLORE

Since HIV/AIDS related deaths constitute 23% of all deaths at RCCH (72), it is important for the hospital management to look at the availability of support structure for the registrars to counteract traumatization and professional burnout.

The issue of the continuity of care deserves urgent attention and will have to be addressed in close collaboration with the primary and secondary level of health services.

Since the HIV/AIDS epidemic is so wide spread and so many professionals are involved in its treatment, a quantitative study is suggested to determine whether the broader medical community identifies with the above findings. If so, strategies aimed at reducing the above factors influencing a doctor-child-parent relationship should be implemented in order to enhance the well being of both the medical professional and his/her patient.

THE QUALITY OF THE PATIENT'S LIFE

RESULTS

All the registrars, who spoke about the subject, were particularly sensitive to a patient's suffering.

- I'm fairly comfortable with the idea of setting goals of treatment and not overstepping those in the interest of medical error and futility. In some situations, and obviously in the setting of chronically ill children, one tends to go on the side of saving lives and doing as much as one can. But we're talking about chronically ill children. I think, also in paediatrics, one has to be aware of quality of life issues.
- Generally the kids that die, I think by and large they should die. They've got awful illnesses and if you do sustain life this is going to be horrendous or they will be severely mentally damaged. So that is not very emotional for me when many kids do die. But children that you get to know a bit better, that becomes emotional, that have been under your care for a while, and it's always emotional for a doctor or, or for me.

The involvement with a child who suffers from a chronic fatal illness makes a doctor question his/her management. Should one continue with active and vigorous treatment or should one allow the patient to die in comfort and dignity? It is a rather difficult question, which sometimes may create an internal conflict, particularly when senior colleagues' opinions differ.

- People have different opinions. Some of them are sort of more pro-life and more active with regards to intervention than others. I'm not sure where I stand. What you can also do, you can sort of involve the person that you agree with more.
- Quality of life is important to me. I think I'm more sensitised to it because I work with disabled children. When it comes to small babies with intracranial haemorrhages and stuff like that, I follow them up, I see the eventual outcome. I put in less intervention with them than other people would be.
- (Talking about morphine) I'm not into use of euthanasia at all. I'm just into letting patients go off in comfort and dignity.
- By and large people are extending life in paediatrics. They're prolonging it. At times I've been in contrast. I sort of thought to myself to stop the suffering now, let the child be. I don't think it's right for senior people to see you as halting the process. They start wondering whether you're really gonna pull your way to this child or not.

Although extending life is a principle in paediatrics, the registrars are very aware that it may invoke iatrogenic side effects and contribute to further suffering.

- Part of the problems was iatrogenic. I was deeply suspicious that she could have got away without surgery on a conservative management and then it would have been back to a position whereby she still would have aplastic anemia. Cyclosporin had never cured that anyway. It didn't seem to be making much difference. So, there was a sense of additional burden as having been part of the team.

The registrars find it very difficult to determine when to withdraw active treatment for two reasons. Firstly, the active treatment is associated with a sense of a well-performed professional duty, which contrasts with a concept of psychological care. This care is immeasurable and illusive and the registrars are generally not competent in providing it. Secondly, active treatment provides a doctor with feelings of comfort, being in control, and being able to offer the patient some tangible care. It is difficult to refrain from this mode since it implies some sense of guilt and acknowledgement of one's limitations.

- You get to a point in many of these chronic illnesses and extremely sick children where you have to make a decision about whether you continue therapy or whether to withhold therapy. In this case it was decided to make the child as comfortable as possible. No more needles, no more invasive procedures, not for any active resuscitation. I always think it is the biggest step to take in these kinds of children. What we try and do now is make ourselves feel better by keeping the child alive because that's easy.
- In many ways keeping the child alive - it's a good idea because it keeps you morally upright. Because we have this need to keep things alive and keep ourselves feeling good, you tend to go further than you should. It's an incredibly difficult balance, and once you've taken a step to do something, then to come back again, relook and

say: "Enough" it's the most difficult situation. You often get onto a roller coaster. You say: " Well that's the last thing we're gonna do" and it doesn't work. Then you think: " Well, let's just try one more thing". It's so difficult to get off the ride once you're on it, and I think in some respects the children, their ultimate care in a terminal situation is impaired by our own need to keep things alive, and I think that's inherent in everyone.

- We've known children who stay alive for five or six years. Now we need to try a new restorative procedure when we should really be stopping and saying that there's nothing more that we can do to that child. If we then lose that child, in fact it happened a month or two ago, then you blame yourself for actually putting the child through all these operations, intensive care struggle and the terrible death on the ventilator. Then you feel guilty because you had attempted it in the first place, but the other option, of course, is that you leave the child and the child then dies a long prolonged death of cyanosis. So, it's a difficult.
- It's more comfortable for us to do something and make the child die in the process of doing something than to let the child slowly die.
- We go so far because that's why you're doctor's in the first place, because it's to help as much as possible in the situation right now.
- You see a very blue child who's struggling and you try everything you can. But you don't have that perspective sometimes that you should really just stop and let the child die peacefully. Probably the most difficult situation is that fine line between: can you actually help the child now or should we just leave it.
- Kaylin, for example, she was dialysed, she was then haemofiltered, she was ventilated, she had three or four chest drains in, she had a catheter in, she was just covered in stuff. Each thing we added seemed to be the something else we could still do; and there was always the whole thing of if we just haemofiltered her then things would start turning the course. I tend to be a little bit more understanding of having all those things, but I'm also a person who has sort of a level and when you get to that level then you realise that you just can't do anything more.

In order to avoid that kind of negative emotions the doctors raise an issue of what I would call 'acceptable' death, where death would be allowed should a patient experience a marked disability, congenital defects and long-standing suffering.

- A lot of kids who die have a congenital problem. A part of me is happy to see them go because of some miserable existence and a very tough one for everyone, the parents and them. So, it's not traumatic to me at all, and it's not particularly moving. It depends on the parents. If you can have some insight with the parents, then that can upset you. It's not a joyful thing to go through with. A long resuscitation in a previously healthy child is normally successful. Kids are very resilient and they bounce back. But, if I see that they've got a chronic illness and

they're extremely sick, (death) it's a blessing. Certainly the parents don't see it that way, but from the medical point of view you can see it's the end of the road, fortunately early rather than late.

- He passed away this morning. What saddens me is maybe I feel sorry for him not being there anymore. I feel sorry for his parents, for his brother and sisters, for the suffering and for the hurt they all feel and for him. He's just had 16 years of life. On the other hand, there's relief in the sense that you know the suffering has ended. You know he was in hospital frequently, short of breath frequently, bound to a wheelchair, not being able to move.

END - OF - LIFE DECISIONS

The end-of-life decisions are closely related to the patient's fatal condition, suffering, as well as economic factors. When these decisions have to be made, they are usually discussed by the whole team.

- If you have to take such a major step as change in the management strategy from active to comfort, it's not easy. It's not passive. It's still active. But there comes a point in which all we want to do is maintain the patient's comfort. And when we're at that point, that's the point of surrounding life and death (which) doesn't bring death imminently. Reaching that point can be many months sometimes, it can be many weeks. It's very hard to predict the end. So we take it (end-of-life decision) as a group.
- It's difficult to accept (death) on an emotional level, when there probably is treatment available in an ideal setting. The fact that these children are not going to receive full treatment is somehow also related to their social setting, to the country, to the availability of resources. So, that's quite a difficult thing to deal with, but it's the reality.

More difficult decisions are discussed during ethical meetings. However, one wonders what factors impact on the final decision.

- It's such a luxury (discussion forum). I hate the larger forum, the ethics decisions where they discuss things ad nauseam for hours and hours. I think you have a gut feel within yourself, and obviously you can't allow it as a blanket policy. People are running mad with their gut feels, but I'm happy with mine, so I don't have a huge conflict with myself.

The registrars felt consultants influenced most such decisions. The consultants have more experience and knowledge, as well as remaining at a certain distance from the patient, which enables them to decide on the matters more objectively. The registrars respect these decisions on most occasions. There are however instances where their views differ from those of the consultants'. It occurs when the registrars become more personally involved with the patient.

- I'm not at the top of that tree or that triangle (decision makers). It is easier to the extent that you don't have to make the decision yourself, but you always do make your own decision. And if you don't agree that's not easy.
- Sometimes I've regretted these decisions (those opposite to consultants' decisions), one in particular. A cardiac kid that I thought should die and stop suffering, has done well. Thank goodness, the senior decision prevailed. That's why they're senior and I'm junior.
- The child-parent unit is very important. The more you know a child, the more you've actually been through all kinds of operations and difficult times with the child, the more difficult it is to stop sometimes.
- Among the staff, there maybe are disagreements and attitude problems than any practice because one of the principal team members takes the view that there is no value in suffering; and that if he was given a legal choice, he would terminate life earlier and see that a patient would never suffer, giving permission, etc. Whereas myself and one other member take a view that not only is that completely unethical and illegal, but that there is value in life, even if it is suffering life. So that is an agreement that we agree to disagree on. We are different. We talk often about these things. There is a difference in approach at that level. There's no difference in approach that we would give adequate analgesia, that we may sedate the patient, or at least take away the sense of shortness of breath, which may reduce the respiratory drive but wouldn't stop it.

The registrars generally feel they should not voice their opinions or objections in terms of decision-making since they do not possess the necessary experience and knowledge. They also believe they can not influence the decision, particularly at the level of a junior registrar. One registrar was of a different opinion and gave a positive example of his influence on the treatment of one of his patients.

- I was a very junior person, compared to a very senior Prof X who was in charge of him, so you can't really say what you think in terms of that type of decisions. Maybe also I just didn't have the kind of guts to say it at that time.
- (Decision making) It's done around the bedside and there's three consultants and one junior registrar. You're not gonna go against the tide. You could if you want to. It depends on your nature.
- The surgeons were going back and back and back. There was no hope situation. There was no chance that the patient with almost no white cells was going to make a reasonable repairable improvement.
- I started by speaking to the oncologists and haematologists. I went to her and said: "We are caught in no win situation here. We've been back into the same symptom four, five times. Every time it's broken down initially very slowly and later you're gonna repeat laparotomy and there's almost an immediate breakdown. We've got into cul-de-sac. I don't believe we could get out of it". This child has suffered tremendously. This poor mother is going through all of this accepting it, accepting that there is a chance of recovery. I don't believe there is any

more chance of recovery. I believe, as a registrar, we should pull out. And the consultant's answer was that: "You should look at the situation and take an objective view". She looked at the situation. She looked at the child. She went to the notes. She said: "I agree with you. There is no way forward". Together we went to the surgeons and we said: "This is our patient, although she is in your intensive care at this time. We think, given the merit of the situation, there is no way forward. We would like to withdraw care, palliate her". So, we ventilated her by hand all the way down to the unit where she had quiet room, where she could stay with her mother. There was a sense in this decision that I was actually the principle person taking that decision, although it was quite clear that this was not the case.

DISCUSSION

The registrars mentioned the topic of the quality of life (QOL) in this study. They did not specify precisely a meaning of this term, although they mentioned characteristics, like e.g., comfort, dignity, avoiding unnecessary iatrogenic effects of treatment. They spoke about QOL in connection with children suffering from chronic disabilities, congenital defects, and illnesses with long-standing suffering. Although they are sensitive to the issues of QOL, they never mentioned whether and how they assess QOL of their patients. One could hypothesized that they have not received any teaching regarding QOL and that any structured assessment of the patient's quality of life does not take place. It is not surprising since a subject of patients' quality of life is a relatively new one. Tanaka and Gotay's study (66) shows that oncologists and medical students view QOL in terms of pain and suffering. QOL is regarded by most doctors and students as equally or more important than survival. Their opinions and attitudes depend on professional experience. Medical students tend to place more importance on the patient's autonomy and enjoyment. Most physicians reported assessing QOL in every patient, but only one in ten had used a QOL assessment questionnaire.

Despite familiarity with the concept of QOL, the ability to identify futility in paediatric care and regular ethical input, it is still very difficult for the registrars to make end-of-life decisions and to discuss them with the consultants. The reasons for that given by the registrars are as follows.

1. There is a perception among the registrars that the doctor's duty is to treat actively;
2. Personal factors – by providing active treatment, with which the doctor is most familiar, s/he gets a sense of professional fulfilment;
3. Active treatment keeps the doctor 'morally upright';
4. The registrars feel guilty and uncomfortable with letting the patient die while doing 'nothing';
5. Withdrawal from active care is associated with some sense of failure;
6. Lack of recognition of the value of palliative care;
7. Respect for the consultants' decisions because of their seniority, experience, and less involvement with the patient enabling them to look at the patient more objectively.

CONCLUSION

The concept of quality of life, although recognized, is poorly defined and not applied in any structured form in everyday practice. Its introduction, on the one hand may, may potentially challenge the current ways of thinking about active treatment; on the other hand, more defined and structured assessment approach could alleviate doctors' anxieties about refraining from active management and indicate when palliative care would be more appropriate. It would also facilitate end-of-life decisions, which frequently evoke a sense of guilt and failure among the registrars.

The end-of-life decisions are usually made by the whole team, with the consultants being the most influential, and in partnership with the parents, as well as teenage patients at times. They are also discussed during ethical meetings. The registrars tend not to voice their opinions because of their junior status, the lack of substantial experience, and fear of influencing the decision in a negative way. Although such attitude is understandable, by not disclosing one's own thoughts on the subject the registrar deprives him/herself a valuable input that could otherwise be offered by the consultant.

SUGGESTIONS TO EXPLORE

It is suggested that:

1. The awareness of the quality-of-life assessment be raised by implementation of developments in this area, both in the medical curriculum and in daily practice (20,70);
2. The knowledge and value of palliative care be spread and commonly accepted;
3. The consultants be more aware of the registrars' conflicting feelings regarding end-of-life decisions and facilitate a discussion about it.

SECTION II

TEACHING AND TRAINING

Figure 2: Teaching

Results

- The role of medical training in shaping doctors' emotional responses
- Quality and amount of training
- Doctors' professional growth
- Doctors' emotional growth
- Doctors' ideas regarding teaching

Discussion

Conclusion

Recommendations

The doctors spent a significant portion of time on discussion regarding training and teaching around death and dying. They spoke about the value, amount and quality of the undergraduate and postgraduate training, its role in shaping doctors' emotional responses and in fostering their professional and emotional growth. Finally, they briefly reflected on teaching around cultural issues.

Figure 2 illustrates the following themes emerging in this section:

- An imbalance between medical and psychological training of medical students leads to the doctors' suppression of emotions towards their patients;
- The registrars' interaction with patients enhances the doctors' professional and personal growth;
- The doctors' emotional development, influenced by personal losses, parenthood and self-reflection, contributes towards more comprehensive management of the patient.

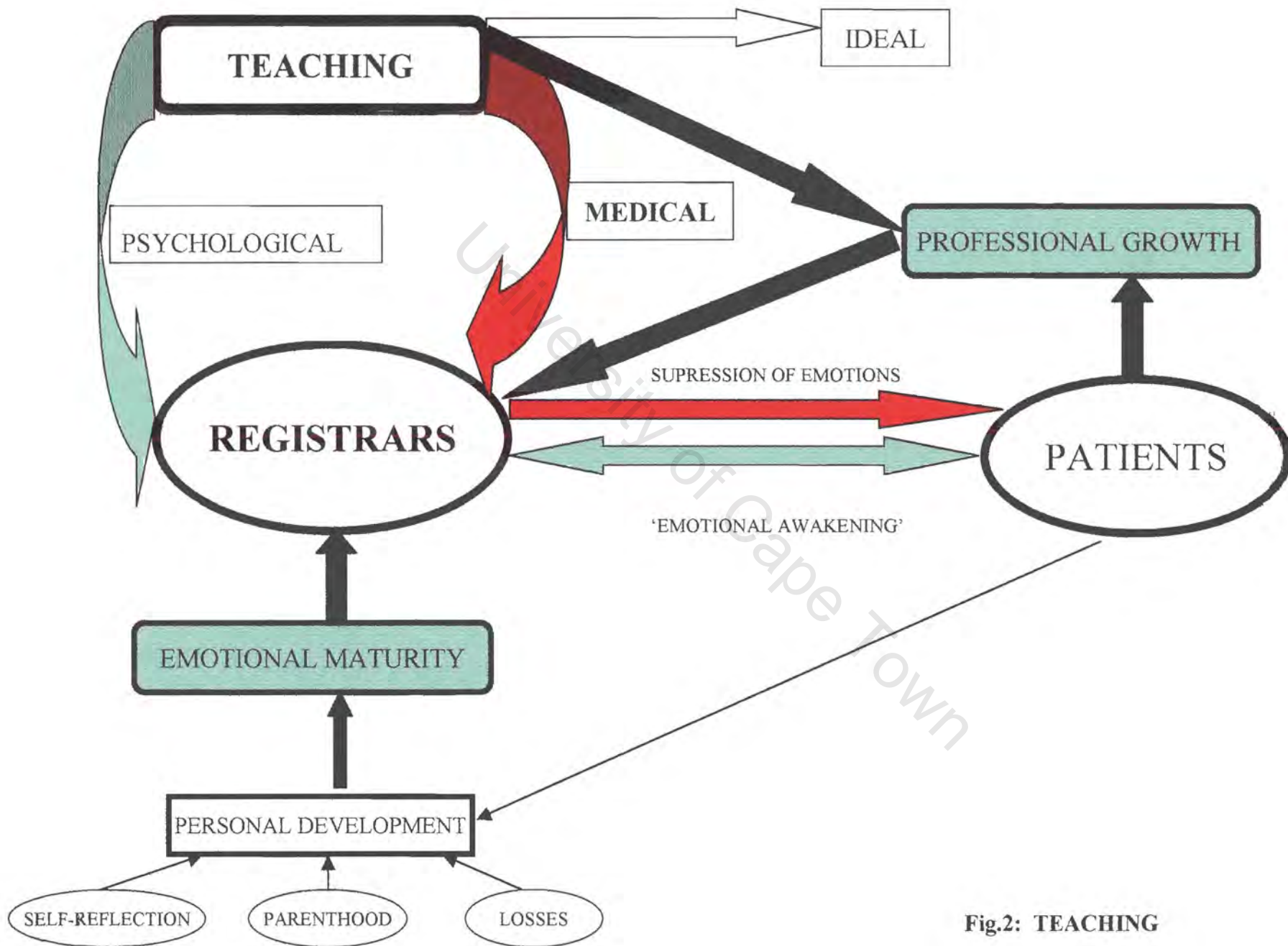


Fig.2: TEACHING

THE ROLE OF MEDICAL TRAINING IN SHAPING DOCTORS' EMOTIONAL RESPONSES

The registrars commented on the impact of medical training on their emotional functioning as doctors. They realize that the nature of the medical profession calls for suppression of emotions that are easily evoked in the non-medical population. To be a doctor means to relinquish an emotional attitude and to pursue active treatment as long as it is possible. It is impossible to maintain such an attitude in the case of a chronically ill child, where doctors' responses become more personalized. The doctors discover then that there is the other side of care and treatment. They are uncertain, however, about the ways of implementing it. Having been educated in a spirit of the active and highly technological management they feel disempowered when nothing more active could be provided.

- The training of medical school and the sort of professionalisation is such that your first response is often as a doctor, and you almost learn to suppress your response as a person. That works particularly well in an acute setting. But in the situation where you've got to know a child over a period, knowing that they have a chronic fatal illness, my experience is that you can't just respond as a doctor. Some of your own personal responses come into play. The other thing is that, in the situation of this kind of illnesses, you come to know the family more and the parents, and you can't really exclude that part in your responses, because often the parents will be involved. Your responses become more personalised because you're dealing with more people.
- One doesn't naturally look at other important aspects of the management or the treatment, particularly from the medical side. It takes a while to realise that there's still other things that we can do, even though the child's not gonna be cured. But we're not very good at that. We're used to doing things. We're trained to do things and fix things, to take blood tests, and that sort of thing. And it's really the other caring side that we're not particularly good at that.
- We're not trained that way. We don't easily make space in our busy day to do that. We assume it's somebody else's job like, I don't know, the nurses, or the social workers, or the psychologists, or whatever. And all the more so, in those situations where the family's not bugging one to do it, it's much easier to overlook it and neglect it when one can't speak the language, or the parents are only there once a week. It's difficult to do it, because it seems more worthwhile to do other active things.

QUALITY AND AMOUNT OF TRAINING

The training that registrars referred to pertained to counselling skills in general, HIV counselling, and a broader psychological training concerning human behaviour.

Most registrars complained of a limited and inadequate under- and postgraduate input regarding counselling skills. They all attended some lectures about the topic but many of the registrars found it insufficient.

- We have been taught again and again about counselling, as students, as registrars. Particular HIV counseling is a big thing that we are taught about.
- You do that during your medical course. It is part of our curriculum. You do it during 6th year, during your psychiatric block about counselling. It has been provided to some degree - that type of courses. But, I think, it is ideal to have that input.
- People gloss over it (counselling skills) as a thing that happens as you get more experience. You know how to deal with it, but no one ever teaches you how to do that, so I don't know how it's supposed to magically happen.
- There's a huge gap, especially as registrars, that we don't have any kind of training in that, whatsoever.

What is the best way to teach the counselling skills when role plays are not taken seriously and interviews behind a one-way mirror require parental consent, which may be difficult to obtain in such situations?

The doctors found that one of the most useful ways of teaching counselling skills is 'teaching by exposure', which is assured by an experienced and empathetic health professional talking to the patient at the bedside in front of the student who is also involved in the treatment.

- Certainly I could do with more counselling skills. I can't remember any specific counselling training. There are some vague memories perhaps of a session in medical school at some point, but it's actually very difficult in medical school for that to really take it on seriously. It's all a role-play. When you get into real life, then you think: "Oh but, what are these parents gonna think, if I'm just sitting and listening, is it okay, if I sit in and just learn how to counsel someone?" Would the parents give consent if they knew they were sitting behind a one-way mirror? The situations in which I've learnt (took place when) I've been there at the time. There's been no one else, or when it's been me and one other doctor, and we've both been involved enough to come and talk, or where the senior person actually needed someone else who'd been more involved clinically to give more details.
- You've seen others do it, and as a student people are always taking these marked scenarios. I remember sitting in scenarios when they talk about death. You lay down layers of things, but when I'm in the scenario I don't go back to anything that I've learnt before, consciously. Maybe that sort of network goes out and my brain links to it. I'm from a good background and the good solid parents, and thus starting the basic skills are there. There is a framework and structure of a medical profession, and you do get trained.

The postgraduate training in counselling depends on the availability and skills of a particular consultant who serves as a role model, and who has time and willingness to share his/her knowledge with a registrar. It also depends on the registrar's time and his/her willingness to participate in counselling sessions.

- A few individuals have set an example to me in terms of making an effort to communicate to patients and to actually get more involved. That I have not been taught but have the examples. Teaching by exposure. I've seen some consultants deal with the situation, a little bit more involved, but again not over involved. On the other hand, I've seen consultants who I consider have been over involved, because I've seen them get so upset and so distraught that they can't do anything else for the day.
- I've sat in with consultants when they've told parents bad news. Some of them are extremely good at it, but it's usually the extremely nice consultants that are good at it. But the bad consultants are just bad, and they haven't seem to have learned any good skills because they just assume, maybe that's not fair, because they are consultants they know how to do that now. And actually they don't know or it seems like it for some of them.
- (You learn how to counsel by) seeing other more experienced people doing it in time. It's difficult at the moment, but you do pick it up. You sit in on interviews with people being told that you'll try no further, you can't do it any further.
- Training's lacking. You don't have the time to sit in with a more senior doctor, especially when you work in the ICU, where we've got frequent deaths, and to see how he does it. You just sit on as a silent observer, and just see how he does it and how the parents react towards him, and doing that a few times, then you do it, and work with the social worker and an interpreter. Not really formal sessions.
- There was a complete mixture of role models in terms of the consultants there, but the ones that I remember the most are the ones that set the best example. They in general were a little bit detached, but more involved than I would have found myself able to be at the time. But then, I was fresh out of medical school, so saw that to be the right way anyway. I think, being generally detached, but still aware, is a good way of doing it.

Some of the registrars approach social workers for further practical input.

- I have actually started working with our social worker. I'll ask her to come with me, and then we'll talk about it together for a while, and then I'll leave her, and she'll talk a bit further. In a sense, I think, maybe I shouldn't have to leave. I should stay in there and hear it all, but that's extremely time consuming. I do think modelling would help, if it was possible, but it would have to be situational. It couldn't be contrived or role-modelled. It just never works.

Another effective way of teaching was provided by videos, followed by a discussion on breaking bad news and grief counselling.

- I still draw tremendously on what, I'm sure, I learnt as about fourth or fifth year student. We had some videos, examples of death scenarios, breaking bad news, grief counselling and so on. I appreciate prof.X. He gave us some lectures on the subject when we were undergraduates. They were actually very useful. We went through the whole points of how to do it, and what are the pitfalls, and what not to do, and so on.

The perception that teaching of counselling skills is inadequate seems to be influenced by the fact that the science of medicine has been prioritised and emphasized during both under- and postgraduate training.

The psychological well-being of the patient plays a secondary role to the medical treatment that has reached a far higher status.

- Getting used to the idea of allowing children to die is quite a difficult new area, which we're not good at. Everything in your training leads you to not pull out. Examples in the leadership in medicine tend to be from a very technological side, where machinery is used to prolong life.
- What's quite ironic is that the senior registrar years are two years, which not everybody does. But quite a few paediatricians and doctors seem to use that phase as a period where they involve themselves in families and in parents, and in relating to children, and sort of preparing for when they might be working in private practice.

Another difficulty in successful training results from the undergraduates' lack of close involvement with the patients. Students, who are not themselves directly involved, do not see the point to that kind of training.

- There's the undergraduate level of medical school, but then you really haven't had that experience with patients. I think, it's more when you're in the registrar training phase.
- There should be some preparation during medical school. But there is the problem with medical school and junior doctors. I found myself a little bit distanced from the patients. They're not your patients. They're the consultants' and the other doctors' patients. In medical school they'll do that kind of stuff. You don't really see the point in it, although you're told that there is a point to it.
- But once you're confronted with that, especially when you have to start counselling parents at three o'clock in the morning with a cot death baby, that's when it hits you most, that you need to be trained for it, and you can definitely be trained for it, and if it happens too often you can crack up, I'm sure, if you take it to heart each time.

The training would be more efficient if every doctor could manage a chronically ill child through the whole course of the child's illness. Unfortunately, three-month blocks do not foster long-term relationships with patients.

- Quite often one doesn't see the end of the patient, because we do a three months block. You can get very involved in a patient and then not know what the outcome is. So, patients that I was involved with may well have died, but there's no patient who I feel that I remember specifically, who I've been very involved in in a long chronic drawn out thing, and then they've died.

The registrars find the theoretical knowledge provides them with a framework that they can lean on while managing families in crisis.

- The more senior you get, you will take responsibility the way you should. The more you explain, the more difficult things are, and you can't do that without some kind of idea. You can do it appropriately using the appropriate skill that actually can be taught to make it so much easier for you. Counselling skills like active listening, or pre-consent, or things like that, things that you can be taught in theory, but it makes so much easier for you to counsel parents, even for the simple things, if you use the skill. And that is something that you can be taught. You can never be taught to be empathetic or sympathetic, or be a nice person, or whatever. But you can at least be taught those kinds of things. I think it is a huge hole in our training.

Psychological knowledge has been noted as important and helpful, not only in dealing with the patient, but also in coping as a doctor.

- You start off and you study the science of medicine, you swim in that whole sea, and with more time you realize how little that works with so many patients. You could do better with a bit of psychology.
- You get better at dealing with the stress of being a doctor. You get better at doing what you do as a doctor. You actually have to harden. That is what I have meant talking about developing at the job. You have to do certain things. That's the people in training, medical students who need to get more psychological knowledge.

Some doctors do not agree.

- You are in medical school to learn the science of medicine; you don't want the art of medicine.
- A lot of people are in medicine because they love the pus, and blood, and stuff like that. Honestly, they are not interested in the mumbo jumbo of it.

DOCTORS' PROFESSIONAL GROWTH

Most registrars stressed that their training, both undergraduate and postgraduate, emphasises biological and technical knowledge and skills. An active style means to concentrate on procedures and pharmacological

treatment. It takes many years of experience and sometimes learning from one's mistakes to acquire and master skills in order to become a confident doctor, and not to experience the feelings of guilt or failure.

- The one thing that changes and it's inevitable is that you get more experience. You get better at certain things from a medical point of view. Things that used to scare me or I found difficult to deal with from a medical point of view before, I'm better with. So that doesn't worry you as much as before. I've also found a niche for myself. I don't think (the experience) has changed the way I deal with the patients. But maybe I'm a little bit more protective of myself, because I see it more often. I won't say I don't get as involved as I used, because I still do that. I still take patients home and I still form relationships with certain children.
- It's terrible to say, but sometimes, you learn from your mistakes too. You know that if I hadn't done this or maybe if I'd done that, next time it will be better; or the patient who wasn't comfortable, and you maybe didn't give them enough of something, then you know that you can do a bit more for the next patient. You learn from your mistakes. You learn from, not necessarily mistakes, but just the experience. It may not be bad for that patient, but it teaches you for the next one. I hope it doesn't harm you too much. I don't want to be a fifty years old paediatrician who says: "Oh, died hey, okay" and move on. That will be the greatest tragedy, because it is a privilege, and we're incredibly privileged to deal with these patients. We are, we really are.
- I always used to attach blame that the reason why all the patients died was because I did something that wasn't appropriate. With time, one can see that that was not actually the case. So then, at least from that point of view, I feel a little bit better that I'm not always thinking that. I still think that, and I still go and check the folder, and I still make sure that it wasn't my fault, and that if I did make any kind of mistake that I would learn the lesson that I won't do it again. But it's not an immediate knee-jerk response, as it was maybe before. A lot of that has just got to do with experience.

In paediatrics, in particular, one also has to develop skills enabling the doctor to interact with children in order to be able to examine them and engage them in a process of treatment.

- You think about medical students. When you start medicine, you're young. You're in your early twenties. You're not really used to (children), unless you'd grown up in a big family, where there were young children. You're not really used to dealing with children, let alone sick children. Plus, you're trying to examine them. Then you try to remember how to feel the liver and all that. It's frustrating. A lot of students, I think, find paediatrics very frustrating because they don't really feel comfortable with the medical side, and they don't feel comfortable with the personal side. Later on, perhaps, when you have your own children and you've also got confidence, you've got medical skills that allow you to play with them (children) without feeling tense all the time.

Once these skills are acquired the doctor has more time to reflect on the patient and embrace him/her more holistically. It is usually at the level of senior registrar that the psychosocial and cultural side of the patient is approached with appropriate attention.

- As you get better at the medical science, you are not so worried. You can reengage in a sort of dialog with the patient.
- Not to sound arrogant in any way, but, I think, the process of going through medical school and then becoming a doctor actually forces one to suppress a little bit of that (looking at an emotional side of a patient) and develop one's medical active style, and then perhaps when one feels one can be better at that and have confidence in that, then one can always redevelop and reopen that other side again. Once you're a little bit senior, you're not quite as rushed around, involved in just doing the medical stuff. That's because a lot of that work is going to be carried out by the more junior staff. Then you start to be able to perhaps develop relationships with patients and parents. In paediatrics, the patients are the children, but the parents are intrinsic to that. On the other hand, it's quite easy not to engage with parents and just treat the child.
- As time gets by, I'm learning more about that (cultural aspects), for example understanding the role of the grandmother in certain Xhosa traditions, understanding that some cultures won't allow a pm when the baby has to be buried, and that sort of thing. In time gone by those would have been sources of frustration to me.
- Because all of us are chronic carers, you can build up the relationship even across the length of cultural barriers, but you sometimes at the end still can't understand why the mothers responded to death in that way: the mother who accepts every single thing you said, and we never get a sense what she felt, and she left, and we don't know.

This attitude coupled with a doctor's personal development contributes to a better relationship with a patient and more thorough and comprehensive management, with no fear of treating the patient in a more 'passive' way.

- I can more confidently allow children to die now and not have a conflict. If I'm managing someone in the ward, I'll start them on morphine as a comfort in their terminal state, and not feel bad about it. I push the staff to give it, because they won't give otherwise. So I'm much more confident. I can ensure that kids will get a decent terminal care, which you can do when you are a bit senior.
- I think you do become more empathic as you get older. At the consultants level, often they approach the age of the parents they counsel. They can see the issues from the parents' point of view, whereas as a young registrar you are caught up in a science.

DOCTORS' EMOTIONAL GROWTH

Some registrars reflected on their emotional development. As young students they are thrown into the world of illness and suffering. They have to acquire a huge amount of medical knowledge and skills, which leaves them with very little time to learn how to deal with patients, how to cope with stress, and finally how to cope with one's emotions. There is very little help in this regard during medical school, despite the fact that early unresolved or poorly managed stressors can affect doctors' attitudes towards their patients at the later stage.

One of the registrars talked about doing 'some growing oneself', suggesting medical students need to have their own separate time to grow, to collect experiences other than medical, and to reflect on themselves before becoming fully engaged in their professional career.

- There's such a huge acquisition of skills that one has to choose through medical school, medical skills, and information, and knowledge acquisition. Clearly, there should be more stuff in the curriculum to do with talking to patients, and to do with dealing with one's emotions and dealing with stress. But ironically, I think, almost more important than that is to try to not create a method straight away and to do some growing oneself before. I think, it's a huge limitation that people place on their lives when they go from school straight into six years of medical. They are faced with the sort of adult or difficult situation at an early age. The effect that has is to blunt them. They're not good at dealing with that, and they then go into patterns, which then carry them through their whole medical career, unless they have a sort of a life before medicine which they can continue.
- You must sort of grow too early and you lose. Quite a lot of medical students have been sort of high achievers at school. They've gone from that straight into university. I took a year off between school and university, and I know some people take a year off half way through medical school, and I think those are good things to do. In terms of the training itself, I think, particularly in something like paediatrics, where not only are you going to deal with children, but with sick children and dying children, there has to be a place for trying to support, and encourage, and teach these young doctors just to vent their feelings about it. Some people are really good at it, because they've got young children, cousins, and they've got young brothers and sisters.

Most doctors did not have a luxury of taking some time out. Many of them, however, have grown up emotionally experiencing a range of events, be it professional or personal. Some experienced their own losses which were far more traumatic than losing a patient. By being a relative one is deprived of a power or control, which the medical professional may still have over the process of dying. Different ways of grieving personal losses provide the doctors with more understanding of their patients' parents' responses.

- The most traumatic deaths I had to deal with were outside my work, personal deaths, where I'm just a normal participant, not a medical (one). I'm not in control. I don't contribute to the process at all medically.
- If you realize how people suffer, what the loss of a child really is to people you have more empathy with them

- Having experienced something (loss) gives you extra skill. Experience is what you have just after you needed it.

Some doctors became parents during their postgraduate years. This experience makes them identify with the parents of sick children and their sadness, despair, and grief. It also helps the doctor approach the parents with more empathy and understanding.

- I thought about this case an awful lot afterwards, much more so than after e.g. several cystic fibrosis patients whom I'd managed for a very long time before they died. It had a lot to do with the fact that the child was the same age as one of my daughters, and in fact a physical similarity and appearance to one of my daughters. So, it was a tremendous identification between myself and the mother of the child. That I had a very powerful identification to the mother appears to be by virtue of my feelings. I suspect it would be in an instance of my child.
- I think my understanding of the issue of being a parent has changed by becoming the parent. I have three children my own, so I think that changed the depth of the experience, but I don't think it particularly changed the approach.
- What's changed now is I have a daughter, and so one's perception of what that family must be going through, and what that child's going through, and their sort of potential outside of what's going on with them becomes a source of conflict (in relation to fascination with biological processes).

DOCTORS' FURTHER IDEAS REGARDING TEACHING

Acquiring knowledge and skills occurs in both formal and informal ways. Doctors' further suggestions regarding teaching included:

- **Teaching counselling techniques (the modes of teaching were elaborated above);**
- **Small group discussions for registrars as part of the clinical teaching curriculum;**
- **Talks by respected experts.**
- Certain aspects of counselling are something that you can teach, like you can learn certain faiths, counselling the parents, or counselling whoever. I've been involved in HIV counselling, and I've been to HIV counselling sessions training. You can be not taught, but you can be told things, like how to actively listen, how to do this, how to do that, open ended questions, etc. You can actually get taught certain aspects of it which can be used as a sort of a rope.

- We've got the registrar teaching group once a week which is an ideal opportunity to have small group discussions, or people that are interested in that to talk to them, or just to get the type of thing that other people are involved with, or how to do it. It's a dedicated afternoon for teaching. 99% of the time is done by strict clinical teaching, and 99% of our work is not strict clinical teaching. In this year we've had maybe one topic: HIV counselling. I don't even remember counselling as a thing.
- The senior registrars meet once a week. We discuss various things, so that space to discuss counselling around death and dying is not inappropriate either.
- We had, I don't know if you know, Professor David Todres – he is from Massachusetts, and his big thing is about ethics and end of life decisions, and he came here just as a visitor, and I got him to talk to the registrars, and normally the talk goes on for an hour, and he spoke to us from half past three to half past four, and he left a quarter past seven that evening because all the registrars were asking him questions, and he kept saying he has to go, and somebody would say: "We really need to ask you this, and this, and this, because no one ever asked those kind of questions". He's been there to answer those types of questions.

DISCUSSION

Most registrars in this study reported inadequate teaching about death and dying. This perception has been confirmed by the existing literature. I stress 'perception' since most of the studies are retrospective and examine subjects' perception of the teaching offered. The trends in terminal care education have shown a steady increase of courses in the last 30 years, yet the perception that this is inadequate remains unchanged (3,4,29,32,38,44,55,53,56,57)

What could be the possible explanations?

1. The amount of teaching in this regard may be in fact very limited. There is not a balance between the biological and psychological knowledge that should be acquired by students. Thus, with a predominant stress on biology the psychological training is regarded not only as limited, but also as secondary and not important.
2. Even if the teaching was very balanced, the everyday practice of medicine needs to show its implementation. Not only experienced consultants, but also doctors at any stage of their professional career should serve as role models. As registrars noted, it seldom happens.
3. The Cartesian split of body and mind, perpetuated for so many centuries, may leave not only students, but also physicians in general with a perception that the psychological aspect of patient care should be left to mental health professionals. Such opinion was mentioned by some registrars.

4. Timing of teaching seems to play an important role. If it takes place in the early years of medical school and is removed from the clinical context, it does not fulfil its expected goal. The registrars suggested that, in order to be receptive enough to that kind of training, one needed to be involved with the 'real' patient as part of a team, to interact with the patient, and to accept all the challenges of end-of-life care. Some registrars stressed that one also needed to attain a certain level of maturity himself/herself in order to treat the issues of death and dying with due seriousness and respect. The reflection on the topic appears to take place once the registrars attain a confident level of clinical competence in the biological management, or once they themselves go through trying personal experiences, like their own losses or parenthood that influence their personal view points and attitudes.
5. Classical teaching methods, like lectures, do not seem to be effective. The most valuable methods listed by the registrars, and confirmed by the literature, are teaching 'by exposure' in the 'real' situation, discussion groups that refer to a patient managed by a particular student or doctor, and videos depicting principles of end-of-life care in the clinical context.
6. In the content of teaching the registrars frequently requested counselling skills. Yet on the other hand, it was the counselling skills that they were taught most often. This discrepancy could be accounted for by the registrars' broader need for general communication skills with their very sick patients and/or their distraught parents.

CONCLUSION

Education about end-of life care has to become an integral part of the medical curriculum. Its implementation has to be well designed with due attention paid to its timing, method, and content. It seems that teaching general communication skills with the patients and the role of the doctor in this interaction could be introduced in earlier years of medical school. Teaching about death and dying seems to be better received in the later undergraduate and postgraduate years. Optimally such education should be multidisciplinary in order not to perpetuate the body-mind split. Positive role models could demonstrate pride in what the doctor is able to accomplish at the end of the patient's life. Fostering the students/doctors' self-growth should be a never-ending process with the emphasis on open communication and sharing experiences among medical professional themselves. By implementing the above strategies the end-of-life care would be able to occupy a valued and respected place in the practice of medicine. Should this happen, the doctors will be able to derive more satisfaction from providing end-of-life care and protect themselves from professional burn-out.

RECOMMENDATIONS

Since the study shows that teaching by 'exposure' is the most effective and most valued by the registrars, it is recommended that the consultants pay more attention to psychological aspects of a child's management and serve as role models to students and registrars.

The registrars would also benefit from longer than three-months-rotations, which are often too short to treat the patient throughout his/her illness.

The researcher intends to offer a monthly session to all interested professionals, in which she would interview a sick child and discuss the findings with the group. The aim of such a session would be the presentation of child interviewing techniques, developmental interpretation of the content of an interview, developing and fostering communication with an ill child, and providing more understanding as to the impact of the illness on a child. It is thought that in this way a gap in teaching of communication skills could be addressed.

University of Cape Town

SECTION III

DOCTORS' INTERACTIONS WITH A DYING CHILD

Figure 3: Doctor-patient relationship

Results

- Bonding
- Doctors' perception of a dying child
- Discussing death with a child
- Doctors' emotional expression while interacting with a dying child

Discussion

Conclusion

Recommendations

Most registrars discussed at length their relationship with the patient. They paid particular attention to the bond they develop with the patient and factors which affect its quality. The registrars also described feelings the sick children evoke in them. Finally, many registrars talked about their difficulties with raising the topic of death with their patients.

Figure 3 depicts multiple factors, on the doctor's and the patient's side, influencing the quality of their relationship. The doctor's personality and emotional experiences impact on his/her bonding with the patient. The child's characteristics, such as: personality, age, neurological condition, duration of illness, and parental involvement will further enhance or hamper the development of the doctor-child relationship. The registrar's knowledge, clinical experience and anxieties around death affect the way the registrar perceives the child's emotional state.

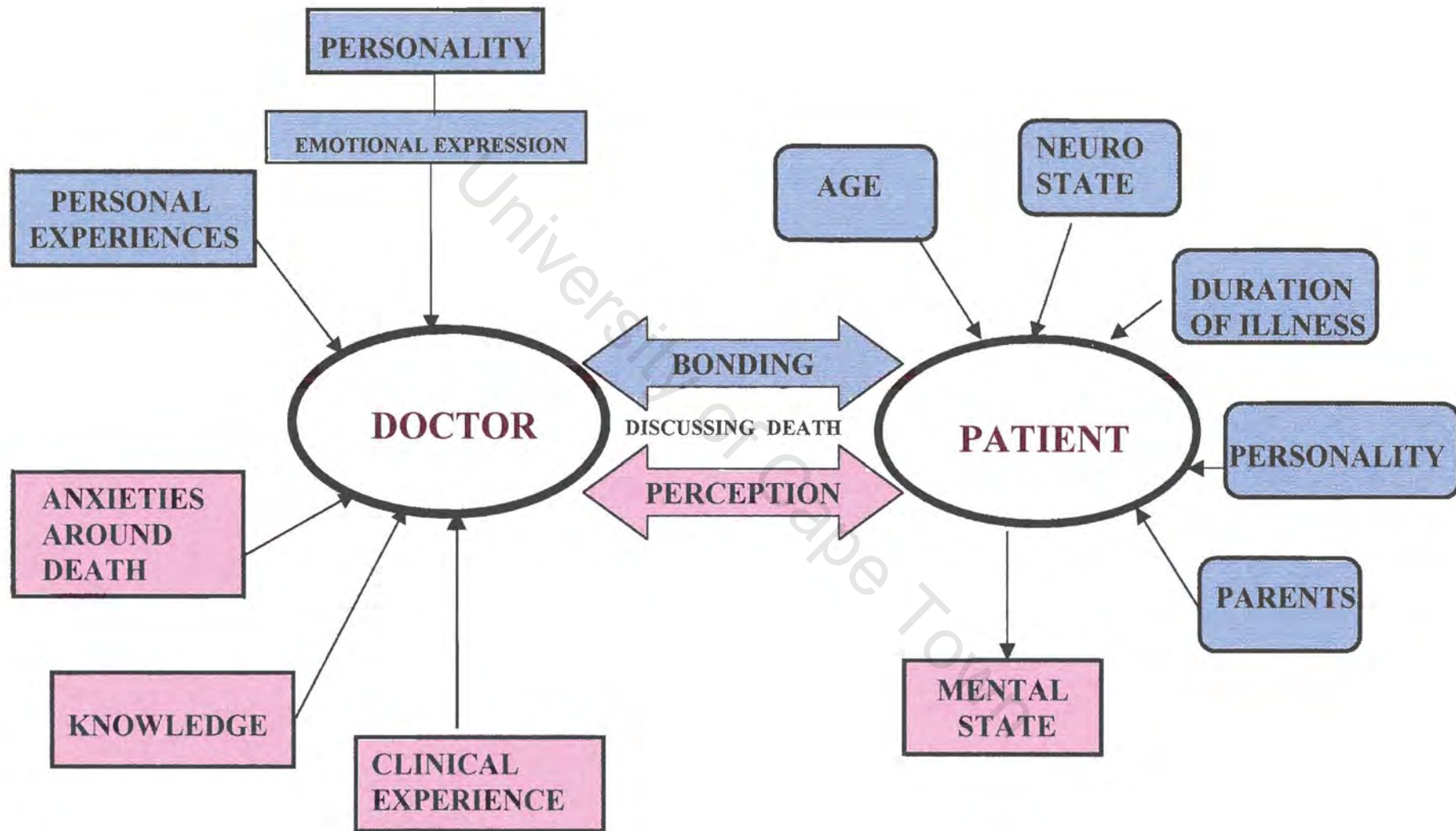


Fig 3: DOCTOR – PATIENT RELATIONSHIP

BONDING

The registrars pointed out that the quality of the relationship with the patient is determined by several factors. They mentioned the duration of illness, patient's age and personality, his/her neurological state, the doctor's relationship with the patient's parents, and the doctor's personality.

DURATION OF ILLNESS

Chronic illness itself implies repeated hospitalisations and prolonged treatment. The longer the illness and the more time spent with the patient, the more involved the registrar becomes.

- So, there is a build up of time and when they're in the hospital, the parents frequently stay with them. So you see more of them. With the result that, I think, it's just a passage of time and the sharing of a very difficult situation.
- The patient had a very tough battle. By seeing him every day and managing him over each hurdle, obviously you've got quite close to him.

AGE

The registrars commented that the nature of their relationship with the patient depends on the patient's age. The deeper relationship develops with a child who reciprocates feelings, irrespective of age, and who is verbal.

That implies that most neonates in an ICU setting or very young children are treated rather instrumentally.

- A premature baby on the ventilator is a thing rather than a person in many ways. I don't mean it callously. I mean there's a sense the child hasn't given me any feedback for bonding. There's been no eye contact, smiling, cooing, babbling, and so on. The child has a plastic tube in its throat. So, there is no realistic ordinary bonding that would occur between an adult and child. Occasionally you've got to bond with a child who's been outside the ventilator and has an eye contact, and has given you feedback.
- The kid that comes to mind is one who died of a cancer, but I was probably more attached to the mom and the family than I was to the actual child, because they're very young. You do become attached to them, but you don't have intimate conversations or anything with the child, and generally they get to dislike you because you're always hurting them.
- We have the babies (in neonatology). If they are going to die, generally they die quite early on. I don't wish to form any close bonds with them, to be honest. I don't think that it's advantageous to do it, and I don't have a

problem with not doing it. Some people can't help but get emotionally involved, but I find it very easy to be a little bit detached, but not completely detached.

The older children with more developed personalities and language skills reciprocate attention given to them, provide doctors with more feedback, express their feelings in a more understandable way, which is more conducive to developing a better relationship.

- For a one-year old child, she was actually very well advanced. She was very happy, friendly. She had a character of her own at one year.
- Your relationship with the child is limited by their developmental sort of being. We have certainly lost older children. It's often much sadder because you develop more of a relationship with them because of their personalities.

Although verbal skills are highly valued by the registrars, they noticed that they are not always sufficient, particularly in the case of chronically ill adolescents who may remain uncommunicative, unapproachable, and requiring extra skills from the doctor's side.

- Adolescents allow one to have a verbal relationship with them, whereas with babies and young children, you focus on the medical things because you don't have to talk to them every time you see them.
- I don't feel very confident at this stage in speaking to difficult adolescents or sick adolescents. It's something that I want to be able to develop. Those adolescents, who remain communicative, I really enjoy talking to because I feel I can connect with them. But the ones who are very difficult, and go through difficult times, and who are sick, where the illness is progressive, it's very difficult, and I really need to learn skills about that.

NEUROLOGICAL STATE

Since there is no reciprocity between the registrar and the child whose consciousness is impaired, the doctors treat them in a more mechanical way.

- Often there were terminal diseases. Kids are not always lucid, and it's difficult to interact with them

PATIENTS' PERSONALITIES

The doctor-patient relationship is enhanced by positive responses from the child. The registrars identified several strategies that children use towards their carers. The children use humour. They may become protective of their

doctors and may express their feelings of love for them, treating them as a parental substitute. The children may also express their dislike or hatred of doctors, particularly during painful procedures.

- Children do that (laugh) for you. They make you laugh all the time. So we're lucky. We are lucky.
- I knew the day that he was leaving that I would never see him again. It was just gorgeous this little child. He came in and he used to come running to me and knock me over my feet. He said to me that, after his mommy, and his daddy, and his new baby sister, he loved me the best in the world. He was that kind of a child.
- Then he left and said not to miss him because he'd be back. His mom phoned me two days later to say he died quite peacefully
- He (a 5 yr old child) actually accepted everything that happened to him very easily. Not easily, because he hated the tubes, and he hated this and that, but it was never that he took it out on us, as the staff.
- Often children change. The minute their mothers come back in the picture, then they kind of reject you. They didn't want to sit with you when you work because their mother was there.
- For an 18/12 old you are the devil. They are terrified of you. A lot of them have never seen a white man. They have just come from Transkei. It must be terribly terrifying. One hopes they see you as a caregiver and somebody who is there to help them.
- They kind of experience things. When you come the first time and you take blood they hate you. And then, in liver transplant 3 years down the line they hold their arm like that for you. They kind of realize that is part of their well-being, so to speak.

RELATIONSHIP WITH THE PARENTS

The registrars distinguished three groups of parents: involved, intrusive, and absent. Positive parental involvement enhances the quality of the patient's care. Intrusive parents may have a negative impact on the doctor's relationship with the child. The parents, who are absent, may evoke the doctor's frustration, but at the same time, the doctor may try to overcompensate this absence and becomes more involved.

- There's tremendous variability of the amount of bonding that I do with patients. It largely has to do with the attitude of the parent. If the parents' bonding in a way is not invasive to my own life, I wonder whether, if I feel threatened by the degree of bonding that they are trying to do, I'll back off.

- With kids you attach to the whole circumstance. The kid that comes to mind is one who died of a cancer, but I was probably more attached to the mom and the family than I was to the actual child, because they're very young.
- My involvement became more with this family as a result of the fact that the mother's sister was a friend of mine. So, there was immediately a personal connection. It just made me kind of feel the strongest sense of responsibility toward that family and towards the child to provide them with support and information, and a good experience of what was happening. It turned out to be a very positive beneficial relationship. In this case the patient was quite a small baby. My relationship with that baby was limited. It wasn't really a verbal communication that I had had with that baby. But with the mother and in fact with the father as well we became quite close.
- He was different because his parents maybe weren't around, so I used to be the one who used to sit there and feed him.

DOCTOR'S PERSONALITY

The process of bonding is also influenced by the registrar's personality. Most registrars are very fond of children and approach them in a very warm manner. Some remain a bit more distant.

- And the little kids - you just don't treat them any differently at all. You just care for them as you would care for anyone of the infants who are a one year old. You've got a fair amount of communication and visual contact. The relationship between you and the patient is in many ways a little bit mechanical. It's not a great loving relationship, but to see him sitting there in the nurses arms and then feeding him, and him drinking madly on the bottle you love them, you do love your patient.
- I often take children out for things that they've not done or that they'd like to do. It's the opportunity to bond closer with them than one would, although I feel sorry for them that their parents aren't here. I maybe take those children in the ward and spend more time with them in the ward.
- With adolescents, now, for me it's almost a pleasure. It's a relief, although it's difficult. I like to be able to talk to them. I'm quite a verbal adult oriented person in some ways. So, it's actually very nice to be able to talk straight with adolescents. There's a lot of issues that would go on and you sometimes cannot do that. There's the possibility of having an adult relationship with them. That's what going in paediatrics these days. You have to expand that scope from little babies to adults.

DOCTORS' PERSONAL EXPERIENCES

Becoming a parent enhances doctor's understanding of children.

- (Children between three and five years old) they're playful when they're well. They're predictable. It may also be because my oldest is now eight. So, that's what I understand.

DOCTORS' PERCEPTION OF A DYING CHILD

DOCTORS' CLINICAL EXPERIENCE AND KNOWLEDGE

The registrars ranged in their opinions about younger children's awareness of their dying, from those who suggested they were unaware of it to those who felt they knew about their imminent death. Many registrars observed children's peace and calmness in the face of death. All registrars emphasized that death awareness is determined by the patient's age, with the adolescents being most aware of the disease process and its implications. It seems that the registrars' knowledge in this regard is mostly empirical.

- Children are unaware of the death issue and it's the adults around them - the parents, the grandparents, the doctors, the nurses, who are the ones who show the grief. The children just don't have the ability to show it. I'm not sure even if they had the ability to show it at that kind of age, whether they would. Infants are infants. They're little beings who are just in the process of being made, really.
- (The patient) she's running around and she's unaware of the possibility of death. The one advantage that we have in paediatrics is that either the children are totally unaware of just how sick they are or what their condition is, or the older children, the 8,10,12 year olds with cystic fibrosis or chronic renal failure, are actually aware and yet totally calm about it.
- You don't get the hysterical screaming of adults who say: "I don't want to die, you must do X for me". A child, who's in the process of dying, or who's aware that death is imminent, does not show any violence or true anxiety. They're just incredibly calm about it. It makes our lives much easier. The little ones are obviously totally unaware. It gives me some relief in a way. It's an unaware period. You're developing, and the people who suffer ultimately is not the child.
- What struck me always, about the older kids that you can chat to, is that that's not frightening to them to talk about death if they're properly counselled. And they often see it in quite graphic terms. They read books of angels and nice things. It's very often not frightening, and certainly Enrico was just tired of suffering. He saw it (death) as an end to suffering and it could only be better than where he was.

- The child brings it (a topic of death) to the parents, always, and they know it. The adolescents know. They know they've got a terminal illness. The friends that they've made here, they die.
- During the adolescent phase, he (patient) starts to understand the implications of his disease process itself. Most of them are at special schools where there's a lot of children with similar disabilities, and they're older than they are. They get sort of in a way understanding of the concepts of death, and we see them very frequently, for about up to 3, maybe 3 to 6 months where we form a bond with them. They tell us about their problems, the fact that they become weak all the time and what they're still able to do. They ask the frank questions about death, and want to know what it entails, how long do they have to live, how they're gonna go? Some questions which you have also difficulty in answering, so it's not just the one off patient.

DISCUSSING DEATH WITH THE CHILD

Most doctors stressed that this is one of the most difficult topics. They expressed their uncertainty about when, how, and with whom they should raise the issue of impending death.

- You are never sure that he is going to die for yourself because you're hoping something will work, but after a while you realize you are losing a battle. Obviously, it's not your attitude, but what you discuss is different to the patient. You don't discuss the death unless you are sure they are going to die.
- You try your best. You try hard. You get to really like him (patient) and he gets to like you, and you vaguely get to know his family. Then you go through a horrendous thing of him dying. And you battle and struggle, and you're trying to get him better. And then you realize that he's got a very mature insight into it. If there is any inadequacies in the system they're probably your own, not the patient's. So, you try to counsel him about the place or an event that you know as much as he does. I will also die. It's just like he's died. There's certain naïveté of one trying to tell the other of death. The only skills I have is to make it comfortable during the dying process. But I'm not a religious minister or his mother. Even his mother can't tell him what's death gonna be like. She hasn't died yet.

Lacking confidence in their own skills many registrars prefer to avoid the topic, particularly with younger children. Some of the doctors prefer to listen to the patient and follow their lead, which more frequently takes place with adolescents.

- I don't feel confident in giving the dying children the space to acknowledge the fact that they are going to die, or ask that question, or draw a picture about it. It's clearly an important area. Having read a Kubler- Ross' book, I think that's trying to elicit from children their own perception of their disease and their treatment, and that's a fascinating area. I think we don't acknowledge the extent to which these children know the

seriousness of their condition. We think that they fairly ignorant and that's something what one can do without the family and the parents there, which is the situation we sometimes find.

- I struggle with talking to kids about the feelings they are going to have, even if there is no language barrier, as in England.
- I don't think I've ever sat down with a child and said to them: "You're going to die". I don't think I've ever done that, and maybe it's wrong. Maybe you need to sit down. There's certain doctors who sit down with the patient who's been under their care for the last ten years, who's got cystic fibrosis, and is coming to the end. They sit down and say that you're not well, and we don't think you're gonna come back to hospital.
- I think the most difficult age group would probably be the adolescent age group. I asked the person who was doing the clinic: "What do you do if you've got a child with a chronic terminal illness with a life expectancy of late teens, early twenties; do you tell them? How honest are you with them? Should you rather not tell them about it?" You know unfortunately, the situation is that they all are in special school and in special institutions, and they talk to each other, and they come back from holidays finding out that their friend is not there anymore, and sometimes they become so cynical.
- In oncology there's a few older children. Those, as it happens, haven't been kids that were about to die. But no doubt, I had obviously thought about it and was afraid of it (talking to them about death). It was something that I hoped the social worker addressed.
- I just listen when they (children) talk. The striking feature is how they think and how prepared they are. They've got a good insight into it, as much as you can into death.
- Part of the problem is not so much knowing what to say, I think, but just be sensitive and tactful.

The content of discussions with a dying child seldom concerns death as such. Most often it revolves around technical details of their illness and treatment.

- I do find that it's important for children to know that you know that they're in pain. There's older children who one could've started to speak about death and dying. I've never gone into that field. I've never explored that because most of the kids have been too young.
- We never talked (about dying). He never suggested it and I never brought it up. But we talked about the bad thing in his tummy, we talked about the medicine that he was getting and why it was important to take the certain drugs that he would take.

- He'd say: "Do you want to go back to the hospital on the Monday", but he'd be quite happy to talk about the birds, and the sea, and the water, and whatever. He wanted to be a doctor for a while, but then he also said he wanted to be a baker, and he would just change his jacket every 5 minutes and become something else.
- Just the way he coped with his disabilities, his maturity that was far beyond his age. You could imagine a lesson itself, something which is difficult to go through, and this guy went through it wheelchair bound. And we could even make jokes about him saying how many girlfriends he has, and stuff like that, and he responded perfectly, and vowed to it, and it's very sad.

When the right time comes, some doctors sit down with a child and discuss death. Irrespective of the content of these discussions and the difficulties that they create, all doctors were of the opinion that they must be gentle, age appropriate, and by all means honest.

- With children, you can raise that (topic of death), but it depends on your relationship with the child. When you are comfortable with the child, the child being comfortable with who you are. I think paediatricians are quite good at that. They (children) will ask you questions, they will confront you if you are dishonest.
- I remember saying: "You are very, very sick, and you might die. Have you thought about this?" And I remember him, he was eleven, he would have heard about heaven and a nicer place, and he was very peaceful about it. I think his family had told him about the concept of dying and going and joining other people, and he had lost family members, so I think it wasn't a frightening idea. He was in such agony and had such misery that for him, I think, it was a pleasant experience.
- You can't hide anything. They're even having a competition: who's next to go. So, maybe it's a way of making good humour about a very serious thing and rather than becoming depressed and negative about it. They see the positive side. Maybe they see it as a relief from a poor quality of life and being freed from that. But some of them ask me directly: "Am I gonna get weaker, how am I gonna go, when's gonna be the time?" Some of them say, when they do reach the stage, that they would like to be at their parents', at home. It's something you'd expect from an eleven year old, from a twelve year old. It's suggestive that they've thought about it and they've formed their own ideas. I think, honestly, the approach that I apply is that of honesty. If you want to return a bond and make friendships with the child and a trust with the child, try to be honest. If they find out that you're not being completely honest with them, it's gonna affect your relationship. I don't mean withholding things, I'm not gonna offer talking about it, but if they ask questions, then I'll be honest.
- In a ward you sit down and you talk to them. You engage them, they talk about their lives.

DOCTORS' EMOTIONAL EXPRESSION WHILE INTERACTING WITH THE PATIENT

Many doctors appreciate a long-term relationship with the patient, even in the face of death. They regard it as a privilege. They allow themselves to get emotionally involved, to feel the child's or his/her parents' pain, and to express their own feelings. Several registrars find this kind of involvement rewarding and therapeutic.

- It's a privilege to get emotional with people (patients and their families). It's a big privilege. Discussing death is very emotional, which I don't particularly mind. Emotions – it's part of a job. It's not something that I am scared of. It's one of the benefits of working in medicine, I feel.
- Crying is just a manifestation of what you're feeling inside. And it's not just that I weep, but your eyes get certainly moist, and you get sort of snotty. I have no problem crying. I think it's therapeutic. I think it's important to recognize that as much as you enjoy laughing, you should enjoy crying. The reasons you cry aren't enjoyable, but it is what makes us human.
- You can't cry in a ward round. I mean you can, but I don't. You can cry anyway. I'd only have a cry in a sort of quite an intimate moment with the patient and maybe one or two other people. But I certainly wouldn't cry with more.
- One mustn't be so detached as to say: "Okay, well, you know, too bad". There are some things I've had to learn about. It's important to show that you're upset, that it's happened in one way or the other. It's important to show that you're sorry, that the parents are sorry, and to share their grief. It's okay to put your arm around them, or to hold their hand, or something like that, to offer comforting gestures, and that is about as involved as I get. There are times where the whole situation has been so sad that it's difficult to stop myself crying, but I would actively stop myself showing that amount of grief. Maybe it would be beneficial for the patient/ patient's parent to see that I'm sad, but I don't think it would make a big difference to them either way.
- I don't find it hard to cry if I'm really feeling upset. It's not a big thing for me. I don't see that as a big problem, although it's not the most appropriate thing to do sometimes. I've cried at work or I've cried with the parents, not because I've wanted to, but just because that's how it happened.

DISCUSSION

Winnicott said: "There is no such thing as a baby" (71). Paraphrasing this statement, one could say that there is no such thing as a patient meaning that patients can be understood only in the context of the doctoring they receive. All doctors referred to bonding with the patient as developing an emotional connection between them and the patient. They

described several factors which make the bonding successful. These include: the long duration of illness enabling the doctor to get to know the patient and appreciate his/her personality, the lucid neurological state allowing for some emotional reciprocity, the patient's age with a stronger bond developing with the verbal children, the patient's positive responses towards the doctor, and to some extent the presence of involved parents. The importance of these factors has been confirmed by existing research (55). The registrars did not emphasize their own contribution in developing this attachment. It seems that those who are warm and fond of children bond more closely and derive more satisfaction from the relationship, even in the face of death.

This relationship resembles the parent – child relationship. As the parent provides emotional availability, nurturance, and warmth, protection, and comfort, so does the doctor, who at times may be perceived as a temporary surrogate parent. The above relationship falls into a paradigm of the teacher-student model of the doctor-patient relationship, in which the role of the doctor is paternalistic and controlling, and the role of the patient is essentially one of dependence and acceptance (31). This model may be applicable to very young children. It is not entirely clear in this study whether the registrars develop this type of relationship with the patients across all ages. However, it appears to be applied by the registrars on most occasions. With the older children and with the growing awareness of children's rights, the mutual participation model seems to be more appropriate. It implies mutual active participation of both the doctor and the patient. In order to achieve it the doctor must be able not only to develop a bond with the patient, but also s/he has to become fluent in age appropriate communication with the child. Although the subject of communication is pertinent to any ill child, further discussion will be limited to communication with the dying child.

In the last forty years, there has been a change in the willingness of doctors to inform their adult patients that they are dying. The *closed awareness* type of communication, where any talk of death is avoided, and *suspicion* type, in which a patient suspects that the truth about dying is withheld, has been replaced by *mutual pretense* and *open awareness* (21). Wiener's study in 1970 shows that the majority of paediatricians believed that 1) "Children usually know or suspect that they have a fatal illness or serious illness, even if not told; 2) Children should not routinely be informed about the nature of their illness; 3) If a child asks directly about diagnosis he *should* be accurately informed; but if he asks directly about prognosis he should *not* be accurately informed; and 4) He should by preference be asked what his own ideas and concerns are if he does ask directly about prognosis" (69).

This study shows that most of the communication between the doctor and his/her dying patient falls in to a category of mutual pretense, wherein the doctor and the patient know that death awaits, but pretend otherwise. This proceeds to the open awareness when one of the partners can no longer sustain the pretense. The registrar and the child openly acknowledge the terminal prognosis, which allows for meaningful interaction and support.

However, the registrars' open communication with a child seems to be difficult to achieve in practice for several reasons. In order to communicate effectively with children about death (22):

1. The doctor has to possess knowledge of psychological development of a child coupled with familiarity with children's concepts of illness and death;
2. S/he needs to acquire skills to elicit information about a child's internal state from the child him/herself;
3. S/he must realize that effective communication can reduce anxiety;

4. The doctor has to be aware of the existing communication system within the family;
5. The doctor has to come to terms with his own anxieties around death.

Although this study did not aim at checking the registrars' knowledge of children's psychological development, the doctors' comments suggest that they have rather limited understanding of this aspect. Most registrars perceived the dying children as very calm and not always aware of what is happening to them. Although it may be true in some cases, the literature indicates that a terminally ill child usually knows that his/her illness is serious and eventually fatal (6,35,63).

This realization may evoke a lot of anxieties. If the child's questions are avoided or dismissed, s/he may be left with a sense of dread that something is so awful that nobody cannot even talk about it. Left alone to deal with questions, the child may formulate his/her answers based on confusion and misinterpretation. The children try to explain events in terms of their cognitive developmental stage put forward by Piaget. Simmeonson et al. (61) found that sick children's concepts of illness went from the global, often reflecting magical thinking "you get ill when you kiss old people", through to the more concrete ideas that illness is related to specific actions, and finally to more general in which principles were invoked. Brewster (10) found that many children under the age of seven years thought that they were ill because of something they had done.

The children's awareness of their dying occurs at a younger age than in their healthy peers and is born of their daily experiences with illness and with their caregivers. Bluebond-Langner found that: "While children want to express their awareness, they do not want to do so at the risk of being alone. They know that the direct expression of awareness could cost them the companionship of those they want near them, their parents. So to assure their continued presence, they practice mutual pretense" (7,p.65). It seems that many of them may practice mutual pretense with the doctors as well.

Children, contrary to their caregivers, are the best reporters of their internal states (31). Yet, it appears that doctors still pay disproportionately more attention to communication with parents rather than the child. Effective communication with a child requires knowledge and skills in choosing the medium of communication which is most easily used by the child. Most of the registrars used the verbal medium. Some registrars were aware of the possibility of using art or play as an additional medium. They did not apply them, however. This fact could be accounted for by the lack of familiarity with how to engage in such communication, problems with the interpretation of art and play, and the perception that this type of communication is time consuming.

This study does not indicate that the registrars are aware of children's anxiety related to illness and death since doctors neither perceive any signs of it nor tap into it. Numerous studies showed that children, who use open communication about their illness and who understand their illness, demonstrate lower levels of stress and improved coping ability (21,35). Denial and closed communication about the illness can cause problems for the dying child who must work out feelings alone (59)

In order to communicate well with the child one can only work within the families' own existing communication system and respect it. This topic will be elaborated on in the next chapter "Doctor – Parent Relationship".

Finally, effective communication may be hampered by the registrars' own anxieties. This study shows that some registrars feel extremely uncomfortable about raising the topic of death. They prefer to detach themselves from the whole situation and leave such a discussion to somebody else. Maquire (39) noticed that even experienced staff, who openly expressed the wish to be open, have been observed to use distancing tactics regularly. Buckman (11) suggested some reasons for such behaviour, which include fear of being blamed, fear of handling the unknown, fear of unleashing a powerful reaction, and fear of expressing their own emotions. Feifel (Feifel et al., 1967 in 69) adds that doctors in general have above average or excessive fears of death, which could underlie all the above fears.

CONCLUSION

Dying is equally stressful for children as for adults. Yet, this fact seems to be relatively unnoticed by the doctors. The doctor-child patient relationship in this study reflects predominantly the teacher-student model, which does not emphasize the need for the child's active participation in the treatment process. This model does not encourage deeper communication with the child. Since the doctors have limited awareness concerning the child's anxieties and its impact on child's coping, the need for psychological care of the child is seldom identified. Most doctors use the mutual pretense and open awareness type of communication. Their difficulty with open awareness may stem from limited knowledge about the psychological development of the child, insufficient skills in engaging the child, and their own anxieties.

RECOMMENDATIONS

In order to foster a more meaningful doctor-patient relationship it is recommended that:

1. Both Psychiatry and Paediatric Departments review their current teaching regarding the psychological development of a child and communication with the sick child, in order to equip the doctor with the basic knowledge and skills enabling him/her to identify a child's distress;
2. The interviews with the ill child, recommended in the chapter "Teaching", be used as one way of increasing awareness of the child's psychological coping and providing ways of its enhancement;
3. The doctors themselves reflect on the subject of death and their feelings about it, and, if necessary, take steps to resolve anxieties around it;
4. A post for a psychologist be created, whose role among others would be:
 - addressing children with more complicated problems for whom more specialized psychological expertise is required;
 - medical staff education regarding children's psychological development and the impact of chronic illness on the child's emotional well-being as well as psychological aspects of palliative care;
 - teaching counselling techniques and expert advice on how, when and with whom the registrars should raise the topic of impending death;
 - assistance with family counselling and family therapy, if needed.

SECTION IV

DOCTORS' INTERACTIONS WITH PARENTS

Figure 4: Doctor-parent relationship

Results

- Parental relationship with the medical staff
- Factors influencing the doctor-parent relationship
 - Parental factors
 - Doctors' factors
- Support structure for parents
- Parental counselling and communication concerning death and dying
- Bereaved parents
 - Parental behaviour and feelings
 - Funerals
 - Follow-up

Discussion

Conclusion

Recommendations

The registrars discussed their relationship with the parents thoroughly. Many doctors perceived this relationship as vital, not only from a care provision point of view, but also as adding another very meaningful and enriching dimension to their daily duties.

Figure 4 illustrates many factors influencing the interaction between the doctor and the parent. The following themes emerged:

- There are three types of parents: involved, passive and absent,
- The parent-doctor relationship is determined by both the doctor's and the parents' backgrounds
- The parent may empower the doctor or intrude upon him/her and interfere with treatment. The doctor's engagement with the parents may range from very involved to avoidant.
- Support for the parents is provided by the registrars, social workers, and the hospital chaplain and extends to a post-death period. The amount of support as well as its utilisation is determined by both the parents and the health professionals.

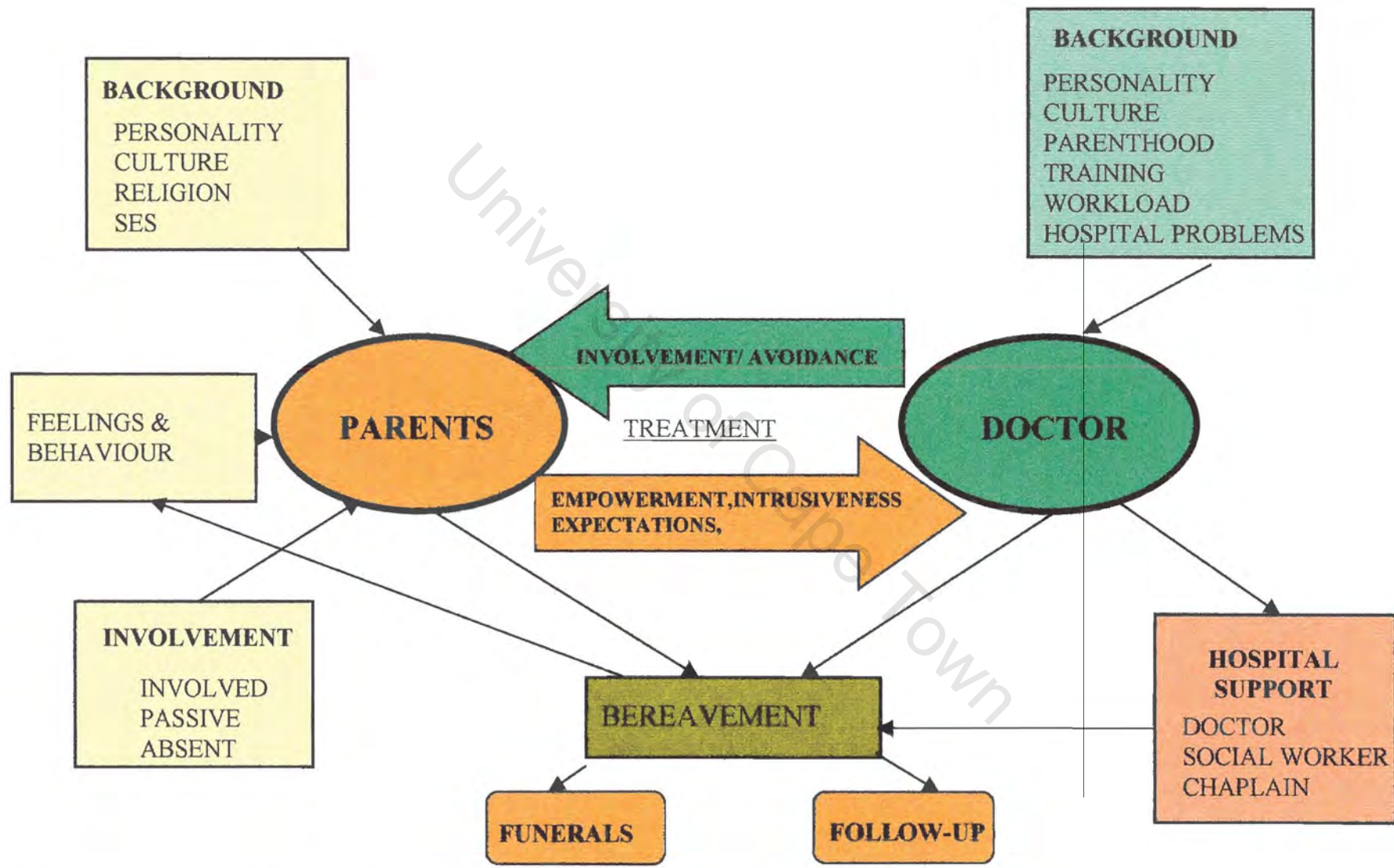


Fig 4: DOCTOR - PARENT RELATIONSHIP

PARENTAL RELATIONSHIP WITH MEDICAL STAFF

The registrars distinguished several factors influencing the development of the relationship between themselves and the parents of their chronically ill patients. They spoke about parental attitudes and expectations, factors influencing the relationship, as well as the doctors' feelings evoked by the parents.

PARENTAL INVOLVEMENT AND EXPECTATIONS

The level of parental involvement in their child's treatment varies. The registrars found that those parents who are more involved have higher expectations of the doctor and the hospital concerning saving the child's life. The involved parents expect the doctor to spend more time with them, which is perceived by the doctors as a demand because of their workload and time constraints.

- I find that those parents that I get more and more involved in, want more and more out of you, and they expect more and more from you, and that's difficult because you've got 20 or 30 patients. I'm their doctor, so I'm theirs for half an hour per day, or maybe 20 minutes per day, or whatever. The way that I can accomplish that is to hear what they say and respond to it, but not to empathise or sympathise that hard.
- It's not an easy discussion to have, but it's a situation which occurs more frequently if you got more involved in the patients. I find it much easier to get on with the day's work and to have a certain distance from the patients (meaning parents).

The parents also want to be provided with more information, but usually accept only these more positive bits, and become hugely disappointed if the course of illness takes a different turn. The involved parents want to listen to a hopeful doctor. Such a parental attitude forces the doctor to continuous monitoring of what he observes and what he says.

- Most times parents want answers that don't exist. They want to know. "Is my child going to live?" You can't say that. You can see parents clutching at straws. You say, "He's a little bit better today". (Then they say): "Oh, then his going to be fine". You find yourself wanting to give good news, but not wanting them to jump to conclusions. So if you're involved in the child as well, then it's all the more difficult because you can see the parents jump to a conclusion, and it might not be the right thing. So, to find the sort of slight balance between giving them hope, but not too much hope, is difficult.
- In neonatology, the parents are usually all 100% hopeful from the start, and there the battle is trying to get them to acknowledge that actually the outcome is going to be poor.

Certain parents, once aware of the diagnosis, read extensively, and empowered by the latest literature may expect the doctor to administer all possible treatments. The registrars, in general, felt stimulated by such an approach. They enjoyed discussions with the parents who knew more about their child's condition. However, they reported that at times that kind of parental empowerment turned into a struggle between the doctor and the parents, resulting in disempowerment of the doctor.

- The parent walks into the room, knows ten times as much as you do about this condition. It's actually not a healthy situation to be in, even for the consultants. The parents start to doubt what the consultants say. (Extensive knowledge about the illness) It's good in the hands of the right parent or good in the hands of the parents who can use it constructively. There's Lorenzo's oil story where the parents find the answer to the problem because they've doubted everyone else, because they've got their own views. I can't dispute there's some benefit in parents doubting doctors, but in general, I think the doctor-patient relationship can be jeopardised by parents going out and doing too much research, and coming up with too much of their own ideas disempowering the doctor too.

These situations do not often take place in the hospital since most parents are described as being passive, with a low level of confidence and demands, seldom asking questions, and seldom challenging the doctors' treatment strategies.

- The expectations and the level of confidence, demands that they have of the doctor or of the hospital, are quite low. They themselves don't often encourage that kind of response from the doctors. They're quite passive and they'll accept a lot. They might not push doctors or nurses to explain to them or to justify things that they're doing.
- Doctors sometimes do try and avoid parents. But I think quite a lot of doctors, particularly in paediatrics, would actually quite enjoy that relationship which is not always there. We try to console ourselves by trying doing the medical side as well as we can, but losing out on the very fulfilling and enriching side, which is the relationship with the family and the parents.
- Coming back to a dying child, the relationship with the parents becomes absolutely crucial because suddenly you haven't got one patient. You've got the whole family too. It's very frustrating in a way where that's difficult to achieve because you don't have that sense of doing the thing properly.

Despite such problems the registrars noted that most parents were satisfied with the care their children received and were appreciative of the medical staff's efforts, irrespective of the final outcome. The doctors also expressed their thoughts that the quality of their relationship with the parents would be different in private practice, which is perceived as a more relationship orientated situation.

- Most of the parents in that situation, and especially when it's a chronic thing, are often very positive towards the hospital, even though they've lost their child, because they've seen how hard you've worked. They know what the child's gone through.
- The reality of working in private practice is that you're forced into more relationship orientated medical care. Whereas, when you're in a hospital, it tends to be much more medicalized, and if you want to you can involve yourself in discussions with parents, but it doesn't seem to be as much part of the job. If you go into private practice, then you have to obviously be able to be much more involved than that, because there's that expectation. Some experience I related to about that little baby was sort of like a private practice experience. It's sort of ironic. I've always felt it should never be something that's just limited to private practice, but somehow that is something of a divide. I think some of that is breaking down, but there's that sense that in private you have to spend time with the family and discuss everything you know and support them.
- Ideally, I would like to be able do it within the hospital setting because, I think, that's what children need and that's what the family need.

FACTORS INFLUENCING THE DOCTOR-PARENT RELATIONSHIP

The doctor-parent relationship is influenced by many factors coming from both the parent's and the doctor's side.

PARENTS

The registrars complained that the parents are frequently absent, fathers in particular.

- In our situation, bonding with the parents - it's not always that easy because the mothers are not there frequently. A lot of them will have to keep working because otherwise they lose their jobs. You see them intermittently.
- The patient was quite unique in that his whole social structure had fallen apart. There would always be a different caregiver coming, and a different church group, and a different person, so in his case I never really got to know the parents very well. But certainly in the smaller kids, that have died with me, I've got to know the parents quite well, normally the mothers, you seldom see fathers.
- Unfortunately, we are frequently in the situation with a terminally ill patient where the mother is not present, and that is an immense difficulty. Frequently we find that there isn't a phone number, or a phone number in a file is fictitious. That's been a problem in the neonatal unit particularly, where you have an X prem neonate.

The mom has been discharged now. The child has been managed for a couple of weeks, but it's now dying. We desperately wanted to talk to the parents about the whole withdrawal of care scenario. What is culturally significant is that they go away pending the bad news, and the way it is supposed to happen is: someone must arrive at them with the bad news. Then they can come rather than they must come and get the bad news. So it does complicate my traditional way of being with them. But we will then find whatever phone numbers we can get hold of, or send someone out, maybe a police or a social worker, or a community worker, or whoever, if they're available, to say: "We are very concerned. Your child is unwell. We would like to talk to you about this. Would you come?" Sometimes they do come, sometimes they just don't come until the message comes up: "Your child has died". Then they come.

- I don't recall frequently feeling deep emotions, and it's usually in a sense again I haven't had the opportunity to bond with the mother. I don't feel I've ever met the mom.

The parental demographic, socio-economic, and cultural background influences the quality of the doctor-parent relationship. The registrars develop a good and stimulating relationship with the parents of similar background, or when they identify with them because of their own parenthood. Multiple differences between the doctor and the parents result in a more tenuous bond.

- (G's close relationship with the parents from the same ethnic group) It was taken just beyond the fact that I was a doctor and the child had cancer. They were the parents that one could speak to on a wider level. It was quite easy initially, superficially, because it meant I could just talk. But subsequently, it is more difficult, more complex because the relationship builds, and when it comes to discussing medical matters you speak in a different way. Because you've spoken about other things, you feel as if you're speaking to a friend or somebody you know well. Their expectations of the relationship and of the information that we could give them as a matter fact increased such that they would bring things from the internet, or they would bring books, and they would want outcome on many of those things. So, the whole way, in which we related with them, became a little bit more complicated and more challenging.
- That I handed a very powerful identification to the mother and what I perceived, appears to be by virtue of my feelings. My sense of grief related to my ability to bond with the child over time and identify with the mom. I guess I bonded with the mother too.
- If the kids die (in a neonatal unit), they are generally too small and they're born to such indigent mothers who're often unbooked and sixteen. If this kid was to survive, it may be cerebral palsy. It has to go back to his Site C Khayelitsha, where he's never gonna see the physio or OT. It's a very different scenario and I'm often not sad about those deaths, not at all. I'm very together about those deaths, and I'm not bonded to these kids, and I don't know the mothers because we just arrive there at night.

- There's a much higher incidence of chronically malnourished and safety deprived children, with parents in very different socio-economic strata that I would find difficult to relate to. So it's not actually that difficult to not get overinvolved in them for me. I'd represent a deficiency, I suppose, that I can't actually do that. In a way it actually protects me and keeps me neutral.
- If my culture is very different from their culture, I guess, I will detach more. I'm acutely aware that I'm not too sure how they're dealing with it (death of a child). I'm not as clear about the implications for them because I'm not as clear about their family structures and who all else is affected.

Most doctors have to make a greater effort in order to communicate with the parents coming from a different culture.

- I've seen that it's necessary to make a greater effort to communicate with the parents who don't speak my language. I think that that's something the doctors as a group have been learning in general. I see it in my colleagues. I also see very fresh doctors coming out who have great insight and seem to demonstrate that from the start. It's something I've learnt, but I think the whole of the medical professions is learning that.

Another contentious issue raised by the registrars, which impacted on their relationship with the parents, was the responsibility for decision-making. Most doctors are of the opinion that this should be done conjointly with the parents. At times, however, parental personality, cultural and religious differences stand in the way of coming to a mutual agreement.

- The mother's a lady who was quite forceful, who knew what she wants to have done. She sometimes conflicted what we wanted to have done to the child. For instance, when the cath lab was broken, and it needed a week to fix it, she couldn't wait the week. She had to go back to Port Elizabeth. We tried to convince her to stay, so we could do the cath earlier because it was important that we did the operation early to save the child. She refused to stay and went. So that created conflict.
- Another frustration springs to mind immediately. This is a mother who was very keen for her child with a life threatening condition to be operated on. She's stuck in a family who doesn't want the child to be operated on. So, she returns to clinic quite often, but we are stuck. She doesn't want to give consent. The more time is going by, the worse the child's condition is going to get. The mother, you can see, is very frustrated and she's in tears often. She is black and speaks only Xhosa. I go through an interpreter. I had the connection. I find she is now in the process of divorcing her husband. Other family members don't want the operation either. They're the people who're antagonistic. They never come to clinic. So it's difficult to encourage the mother to go through a divorce and say: "Yes, get rid of the 'son of a bitch', he can't do that". It's obvious and she can't say that either. It's a very difficult situation. She sees you, she knows exactly what's happening. She understands what you need to do. She understands that the longer you wait, the bigger the struggle the child has to recovery.

- (I dealt with) Jehovah's Witnesses in Neonatology. The baby had very incompatible blood with the mother and was very anaemic. Actually, I had to do a caesarean section to rescue the child. The risk was very high of actually losing the child because of his anaemia. We went straight from the beginning to tell the parents that we'll try our best not to transfuse the child. I was quite cross with the parents for being such hard headed that they will not allow it. It didn't matter what the situation was. They would not allow the child to have a blood transfusion. In the end we didn't have to give it luckily. But then, I got a flack from other colleagues for taking the risk. The child's haemoglobin was quite low and we took a risk with a prem baby with a low haemoglobin, but it balanced.
- Parents can't either rationalise themselves or they can't have the insight. Sometimes they have that insight. Sometimes they don't even have the full relationship with the child. The child might be an orphan. What we try and do then is usually try and make a team decision. Then everybody decides together.

DOCTORS

What contributes to the less successful relationship on the doctor's side? The most frequently cited obstacle is the language barrier, which creates a lot of frustration among the doctors. Any communication in this situation calls for an interpreter. The interpreters are usually available during working hours. However, sometimes problems arise after hours. The presence of the interpreter ensures only a rather superficial communication with the patient. Some doctors feel that working through a translator prevents them from developing a closer bond with the parent.

- I battle with Xhosa, and you can get a social worker, but they're often dying after hours, or there is no one there, or there is no staff, and the counseling is not optimal, particular in Xhosa.
- I find it very difficult if I have to work through a translator. I find it extremely difficult. It's very frustrating. You cannot make a direct connection, a personal connection with people you can't speak the language of.
- When I speak to English speaking people or Afrikaans speaking people, I can understand how much they're understanding and how much they're taking in, and at what level you could pitch the explanation on. If you're talking about difficult cardiac anatomy and you want to explain to them exactly where you want to put the pipe, depending on what level you're speaking at, you can communicate. You can make a connection, a direct connection with almost anybody, but for that you have to get reciprocity. I find this particularly with Xhosa speaking people, that you can't do that. If they speak English very well, then you can and they get it. That's a frustrating barrier at times, and if you go through a translator, there's quite a barrier as well. Some translators are better than others. They can actually sometimes transmit some of feelings.

- And you see the interpreter chatting for a long, long time, and all you get is “yes” or “no”, and you’re really get frustrated.
- We have a lot of the patients in the ward. At the same time we wouldn't see their parents much, and if we do, we wouldn't be able to speak to them on a one-on-one basis. It would be via an interpreter. So, there'd be issues like that, which just prevented easy hour-to-hour, day-to-day talking that one can do with somebody of a similar background. One becomes used to that and works within those constraints.
- Most of the children although they're Xhosa, most of them speak reasonable English. The rest I've bonded with I can communicate with.

Other factors influencing the quality of the doctor-parent relationship included the registrars' workload and sometimes hospital circumstances, which are beyond the doctors' control.

- The whole involvement with the parents in paediatrics is such a big part. But it's a part that is underplayed quite often here. This is real issues, real barriers to some extent. These are fairly practical things, like parents not being there, the requirement for interpreters that is increasingly difficult, just the distance that's created by the situation of interpreting. Also, there's just such a big load of patients in a busy clinical setting, that one doesn't really always have time to spend with parent the way one would want, so you focus on the medical side.
- I felt disappointed that she couldn't just wait a week for us, for the machine. We tried to explain that it's not our fault. We felt guilty that we couldn't treat the child then and there. We couldn't do anything else, but just tell the mother: "Sorry, but you have to wait for a week to do the test that we have to do ". When she came back again, we did the cath. We first thought that she's irreparable and we tried to blame the mother. It was our fault for not being forceful enough to stop the mother from going back to PE. So, it was the guilt and the disappointment, it was not a failure.

Another important obstacle noted by the doctors was the discrepancy between their and the parent's cultural and socio-economic background. The bigger the difference, the more difficult it is for the doctors to relate to the parents.

- Sometimes there are cultural and social barriers that one has to overcome as a result of the situation in this country, whereby a lot of the patients come from very poor socio-economic backgrounds.
- In the South African context, it is extremely difficult in many respects because a lot of our patients are from such different backgrounds. There's language differences. There's a sort of a culture of not sharing between races in South Africa. That is incredibly difficult to overcome on a personal level from both sides, and a lot of parents don't really want to hear your problems. They don't want to hear that you are angry, and that this should have happened, and that should have happened. They want to hear from you that the child didn't suffer. They

want to hear a reasonable explanation. I don't think they want to hear about your pain or your anger. I really don't think they do. That's my impression.

SUPPORT STRUCTURE FOR PARENTS

The registrars referred to two wards where there is a well-established support structure for the parents, oncology and the ICU. The work of the social worker was particularly appreciated there. Many other wards, however, do not seem to be able to provide support for the parent to such an extent.

- In the chronic setup, certainly in oncology, there's a social worker who is well skilled at the treating the parents of a dying patient. The staff are used to it and are very good at it. So the structure is in place for the patient to die with dignity.
- Certainly within the hospital there's zero structures (for addressing parental needs other than medical). It can be really quite horrible, especially now with HIV.

The topic of spiritual support was also raised. The hospital chaplain was perceived as an integral part of broader support for the parents.

- The chaplain on call - she comes in the middle of the night, at a very short notice, to people across communities. She is an Anglican priest and she's come to people from other denominations. What is really nice, she stays sometimes for an hour or two hours sitting. They comfort the parents, so while we sort out things, she does what we don't have the time for, and that is really helpful.
- The spiritual approach in the end makes a difference. They also get the skills in counselling. It is part of their training.
- It (spiritual approach) eases the pain often.

It seems, however, that the spiritual needs of the parents are frequently not thought of by the registrars.

- Little things that are personal issues, like whether you ask the parents whether they would like to have the baby baptised, or "Do you want to call your minister?" depend on the type of registrar and how busy he or she is.
- I do that because of my own beliefs. Some other registrars won't even think about it. They miss the opportunity for the parents to have had that kind of comfort.

- I don't always think about it (spiritual support for the parents). I think D is right, and you should call a chaplain, particularly in the situation where Lucille (the chaplain) is there. She is fantastic. She is very good with the spiritual needs, but again she has, like D, that sort of spiritual approach.
- There's always this question: "How much of my own religious belief should I place on the parents?" Of all these children have been children who come from very different backgrounds. It's not something I've particularly have spoken to any of the parents about or made an issue around about that time. I always ask them if they want a priest, but I don't insist on it just because I would want a priest there. I've been involved in baptising children because mothers have asked at the neonatal unit, and it was 2 o'clock in the morning. She placed their arms around my neck and asked me if I would, and then I would. But I don't do more than that. Often people can use that as a platform to influence the parents, which, I think, is not the most appropriate thing. Maybe some people think that's not the way to do it. I never tell them how I feel. I try to help them.

The doctors also ask a question regarding timing of such support.

- When the child is very sick you hesitate whether to suggest a priest. If they (parents) want that, they welcome it; if not, they don't come back to you.
- All along you're saying to the parents: "Your child is very sick"; and they often will come an hour later and they'll say: "Is he better yet? I think he is much better now". And, as a way of getting across that things are very bad you say: "Look things are looking bad". You might say just that: "Perhaps the child should be baptised".
- The one problem in this situation is that stress, when in fact the child is fairly brain dead, and you've got other sick children in a on the ventilators, and the timing of the whole thing can get quite crucial to a point that you actually can't wait.

PARENTAL COUNSELLING AND COMMUNICATION CONCERNING DEATH AND DYING

It is very distressing for the doctors to watch parents grieve. Some parents may go through a stage of anticipatory grieving while the child is still alive. Such a situation evokes many feelings in the doctor who may himself struggle with their containment. In such scenarios doctors find it useful to lean on a certain theoretical framework or to follow certain rules according to which they could behave and contain the patient's parent.

- In many respects, that what made it sad for me was to see this mother grieving because she only had the child for four months of its life, and she also lost her husband during this process. He was shot. It was terrible to watch her grieving. It was awful, as I feel in every single situation when I had to counsel or tell someone that his/her child has died. You feel absolutely helpless and you try and run through what people have told you in the past: You shouldn't talk too much. Give them the opportunity to talk. But when someone just sobs and sobs you put your arm around them, you begin to feel helpless. You don't know if you should be talking or if you should be doing something. For your own discomfort you tend to talk. I actually find myself restraining myself in talking. I'm there. I comfort them, but at the same time I'm asking somebody to get a cup of tea. It seems the appropriate thing to do.
- The last thing you want to do is to point fingers at people who've lost a loved one, and say: "Pull yourself together. You can do better than this. Your child's died, have another child". That's the most ghastly thing you can ever say to anyone. Every person grieves in different ways. Everyone does it differently, and probably appropriately short in some people and appropriately long, if it takes you the rest of your life in other people. I don't think you ever get over losing a child. I don't think it's ever going to be an event that you're not going to look back on and feel terrible about. It's a grief that's terrible. It stays with you forever.

The practical side of counselling is seldom easy. It seems, however, that most registrars follow a certain pattern. They all try to equip the parents with the necessary information, which most registrars perceive as absolutely vital in the process of counselling. The doctors are prepared to answer the parents' questions, although the content of these answers may not always sound acceptable to the parents.

- One would individualize the approach to parents. My starting point is usually to try to engage with the mother, to try to set them at ease, to be of assistance to them, and to be non-threatening, I think, to benefit the child in terms of what it's going through. It's quite a threatening experience, and the mothers are afraid that this diagnosis that's been made will result in their child being treated in a different way or being sent home. I try to allay that. With the mother, the child's best interests are my interests. Then, I try to give them information which often isn't really what they want.
- Generally, if I'm sort of running through a situation, I tend to just ascertain who they are, whether they're the mother or the father. Usually this is when their child is sick. You just start off by acknowledging the child is very sick right from the start. Then, I say in a short a way as possible what was wrong with the child and explain all the bits that are going into the child. Then, if I can give some suggestion of outcome, in my current job now, I can immediately tell them fairly confidently everything's going to be fine. But if I think of the parents in an ICU setting, I will generally tell them to take it one day at a time, and to tell them that I will only know things one day at a time or even an hour at a time. What I told them now might not hold true tomorrow. In the early stages, as the thing progresses, one can maybe give more information. I don't take them very far in terms of long-term outcome, but I will try and inform them as to what's actually happening now.

The prevailing climate of the discussion should be honest and reality based.

- In parent counselling, while choosing to use gentle words, use words carefully to give parents the whole picture. Trying to protect them from the truth is paternalistic. It's not our job and it's not for us to hold on to the burden of the truth, while withholding it from others. It's inappropriate, and it means that when you are reassuring to someone they can't believe you. I think sticking to the truth is best.
- My way of doing things is to try to avoid them perceiving me as being the guilty party which, I think, is good that I avoid that and that they avoid that, because that would interfere with their relationship with me as a doctor, unless they needed to appropriately place some blame.
- It's not in the patient's interest to pursue another course of treatment. I would like to approach the parents to tell them: "Look your child is in an end stage". We need to discuss matters like: where would the parents think of the best place for their child to be, would it be in the hospital, would it be in a home environment, would it be in another environment, what level of activities is appropriate, what can be offered in terms of analgesia, what level of analgesia is needed, etc., think of almost a hospice care type scenario which we plan very carefully in a number of interventions.

Finally, some registrars commented on the issue of parental attitude towards informing a child about the terminal stage of illness.

- One of the questions that we raise is would they like us to talk to the patient (about approaching death), or would they like to do it themselves, or would they not want to engage the child at all. And invariably, in my experience over the last two years in this country, it's been different in the UK, but in this country the parent would have said: "No". They don't want to talk to them, and we honour that. They don't want the child being involved at all. I don't have a problem with that. I think the parents must be left in command of that. They need to have some big responsibility and that's their big responsibility. We certainly wouldn't override their wishes in this situation. Children are minors. They are the parents, and they know their children. Maybe they try to protect the child from the fear of death. But the child knows.
- It is the hardest of all. It is difficult for them to admit it to themselves that the child is dying. Especially with the chronic child, they have been trying watching the crises and getting over them, and now actually they have to admit it to themselves, and having worked through themselves before they can actually discuss it with the child. It is a very hard thing to discuss that with your child. I find a lot of parents deny whole thing and hoist off that to the staff or start withdrawing from the child.

BEREAVED PARENTS

PARENTAL BEHAVIOUR AND FEELINGS

Death of a child constitutes one of the most profound losses parents may experience. Such an event may precipitate very distraught behaviour on the parents' side, with enormous variety of underlying feelings. The registrars encounter a spectrum of parental behaviours following the child's death ranging from immensely agitated to frozen and unresponsive. There is a lot of anger and denial expressed by the parents in the initial stages following their child's death.

- There's various levels of parental distress. Last week we had a lady who collapsed on the floor and screamed, and shouted, and went completely berserk. That is probably in the end easier to deal with actually because there's something you can actually do. Although it is very shocking at the time, but at least they are letting out their feelings immediately.
- The Xhosa women are often very emotional. They scream, and shout, and thump the floor. I'm not familiar with that culture, although I've seen it many times now. It's still always a bit foreign to me.
- Culturally they are very different around the death. In Xhosa, they've got a huge need for the grandparent to be there, and often what you think the issue is relevant to the parents is not. They're thinking of contacting the grand parent, or aunty, or somebody else.
- The difficult part is going to explain to the parents that their child has died. They're looking at you and they don't say anything. There's nothing to do. There's no response, no direct response. It's just proof stonewall. That's the most difficult thing. They don't thank you. They don't shout at you. They don't do anything.
- We always feel anger. In our experience it hasn't been directed at the CF clinic. But frequently there's the anger directed at people who failed to make a diagnosis initially, years ago. The parents are still angry about all that, as if all that makes a difference. But, nevertheless, there's no reason to come back to that anger now. Be supportive and hear it. We see their anger. They're angry with God, and their genes, and their parents.
- There are times that you have to absorb all of this stuff that's coming from the patients and from the family. There's been another patient for which that is particularly the case, where there's been huge anger directed back at the medical staff by the parents. They deemed that there'd been almost a deception; that they weren't fully informed as to what was going on. They denied the diagnosis. It was very, very difficult to deal with.

- Most of the parents I've come across with disabled children are very good parents, excellent parents, dedicated parents. Sometimes there's anger and they ask why, why did it happen to me, especially when you break the bad news, when you screen a child and this comes up.

Some of the parents, who are feeling extremely bitter and angry, take the matters further and enter a legal route. It seems that almost every member of the staff is negatively affected then.

- The consultants were quiet, but there were threats of legal action. Everybody became very weary of talking to these parents. Even though you don't deal with this child. The junior doctors are the ones who will be taking blood tests and actually managing the patient. It will be discussed in the ward rounds in quite a solemn way because the consultants, they came to actually, take a real responsibility for what was going into the management decisions, because of the family's reaction. They had a number of meetings with the family. Then, we had a few meetings, sort of debriefing sessions amongst ourselves, and afterwards as well once the patient died. The patient died, and that (meetings) was very useful because we actually had to submit statements and just be clear about what everybody's position in it was.

There are also parents who seem to accept fate and are appreciative of doctors' management.

- When the child died an hour after theatre, that next morning the mother came back to the ICU and told the doctors and the nursing staff that's fine that the child died. We tried our best and she tried her best, and that's the way it is. The child was born with a bad heart and it's the outcome. Although you feel quite sad about all these things happening, in the end that's the way it is. The children are born with bad hearts. We try our best.

There are also those parents who feel guilty and very depressed.

- I think it's even probably more difficult with the mothers of these children. You try and bring it earlier. It's no use talking when the child is already dying, and so in a way preparing them that this is the route, which you're can look forward to. A lot of mother's are very emotional as soon as you bring it up. They either don't want to talk about it, or they start crying, and sometimes you cry along from empathy. Most of these children (in neuro clinic) have very good mothers, mothers that are completely dedicated, their whole life geared towards this particular child. Maybe they've got some sense of guilt because this is something, which the child inherited, and they're partly to blame.

FUNERALS

The funeral arrangements present a kind of closure to the parents. It seems that many parents invite doctors to the funeral, which is perceived by the doctors as an act of appreciation and gratitude for their efforts.

- I've attended one or two funerals before. Just the gratitude that the parent's show when you arrive there, the enormous gratitude they show, that itself tells you that how much they appreciate you being there. I think it's important for them as well that they realise that they listened to you. You're just not the doctor; you're also yourself, a friend to the family.

It is impossible for doctors to attend all funerals. They decide, however, to attend the funerals of those patients with whom they had a very special relationship.

- I will go to the funeral if the parents ask me to, if I feel very close to the child, especially, when the parents ask me to. And sometimes they say that the funeral is this date and there. Even if they don't ask me, the fact that they tell me where it is means that they want me there, and I do it for the parents because I've known them. I've become friends with them and it may ease their pain to see me there, seeing how much friends he had, what he meant to a lot of people. If you ask me, by physically going there, if it brings about closure, or if it eases maybe the anger, or the disappointment over what has happened to this child, then probably not, to be honest.
- I go to funerals either from my own point or if the parents invite me. I would go and often parents come back later.

Some registrars ponder whether their role should extend to funeral attendance.

- Patients' parents have invited me to their baby's funerals and I haven't gone. Maybe because she did actually invite a couple of the doctors. She invited about three or four of them and I thought: "No, it's extending the role of the doctor too far. I'm not a social worker. I'm not a family member". Not that social workers would go to all the funerals. My involvement was clinical. There was emotional support, but I don't see it extending as far as going to funerals.
- A funeral invitation - it was her (mother's) way of saying thank-you. You know that she's not blaming us for the death of her baby, etc. But at the same time, if one starts going to funerals of babies, then the community as a whole sees it as: "Oh, that doctor is going to that baby's funeral, what's special about them? Why doesn't he go to other babies' funerals?", etc. You do see yourself as to a certain extent setting an example to the community and to try to treat all your patients as equals. I think it is in fact to the benefit of the broader community of patients and their parents to try and remain a bit detached.

FOLLOW UP

The funeral may not be the last contact with the parents. All parents receive a follow-up invitation. Their attendance depends on the quality of their relationship with the hospital staff and their experience of care, which was provided for their child. Some parents remain in long-term contact with the hospital staff.

- Parents tend to come back depending on the situation in which it (death) happened. What's similar in cardiology and in oncology is that they're long-term patients. You know them for years and years and years, and some patients die when they're 10 or 12 years, but you've looked after them since they've been babies. So, you know the parents extremely well. Of the deaths of the chronic patients that we've had in the last 5 months, we've seen the parents several times.
- One set of parents stand out in particular. They came back quite regularly. They came back to see and speak to everybody and brought the children's clothes for the hospital. I think a lot of it hinges on whether the parents made a relationship in particular with anybody in the unit as such.
- They just don't come back. It's maybe that our social work department is very good and they give them appointments to come back, whereas we just give an open invitation. If you need to talk, come and talk. I've had parents who came back and said: "We just want to say thank you for everything you did for our child, thanks very much". It's very difficult. It's incredibly difficult for someone to come and for me to deal with someone coming to see me to say thank you. Their child has died. You've done what you can. In that sort of circumstance I never know what to say.
- What we do in cardiology now is we make an appointment actually to see the parents again. It's usually our consultant with a social worker. There have been certain patients in that particular group that I've been involved with. So, I would sit in as well or it's just me and the parents. Some parents have come back on their own for certain reason. Sometimes it's hard for the parents to come back to the hospital too. Then, you don't see them again or sometimes they send a card or something at the time of the anniversary of the death.
- In David's case, it was a bit different to the general rule. His mom would always bleep me, or phone me, or tell me what was happening with his younger sister and the baby.

DISCUSSION

The registrars talked about three types of relationship that they developed with the patient's parents: 1) mutual involvement, 2) passive, and 3) avoidance. Sahler et al. (55) distinguished the same types of relationship between parents and the interns. According to them, the type of relationship was determined by the child's age, his/her neurological condition, and the duration of illness. In this study, apart from duration of illness, the type of relationship seems to depend predominantly on the parental involvement.

A mutual involvement developed when the parents were present and active in terms of eliciting information from the doctor about the child's condition, collecting information about the child's illness from other sources and discussing it with the doctor. This resulted in well-informed realistic expectations. Factors that were conducive to the development of

the relationship included no language barrier, minimal cultural gaps, parental religion that does not oppose certain medical procedures, and a relatively good socio-economic status of the parents. Such a relationship constituted a source of satisfaction for the registrar because of closeness with the parents and better understanding of their situation as well as identification with the parents. At the same time the relationship was a source of more pronounced grief responses in the case of the child's death.

A passive relationship developed with the parents who were seldom present or 'passively' present; who accepted everything about the offered treatment without any attempt to challenge it, fully understand it, or even discuss it. Such a relationship often developed between the doctors and the Xhosa speaking patients. One wonders, however, to what extent this is a 'real' passive relationship, and to what extent this superficial passivity results from the parents' lack of familiarity with the Western medical paradigm, different cultural beliefs about illness, and from language barriers (64). On the other hand, the individual style of the doctor and the stereotypes s/he might hold about the patient from a specific background also determines how and what symptoms are presented. (48). Death in African tradition is not seen as the end of life, but as a physical separation from other human beings towards joining the ancestral world. The hospital is not perceived as a place conducive to preparing for death because: 1) it is not a home where the soul ideally should leave the world; 2) the wishes of the dying person (in this case the parents of the dying children) are not easily taken into account; life support machines interfere with the natural process of dying; and 3) the traditional approach to treating the dead is difficult to respect, e.g., post-mortem examination is against the beliefs, where it is important to bury the deceased as a whole. (47). With such different and conflicting attitudes towards life and death passivity might constitute the outcome of multiple misunderstandings on both sides.

Finally, an avoidance relationship developed in a situation when the parents were overinvolved and intrusive, when additional knowledge they obtained about the illness resulted in unrealistic expectations and served to undermine and disempower the registrar.

Both passive and avoidant relationships constituted a source of frustration for the registrars. At times, the passive relationship appeared to be convenient for the doctors because of their workload. Yet, they agreed that such approach was unacceptable.

It is interesting that in Sahler's study (55) the interns' relationship with the parents depended more on the child's characteristics than those of the parents. In this study, the registrars clearly distinguished between the relationship with the child and with the parents. The factors, like child's neurological state or age seemed to have no influence on the registrars' relationship with the parent. However, their relationship with the parents might affect, to some extent, their relationship with the child, e.g., it may be difficult to develop a close relationship with a child who speaks a language the doctor does not and whose parents are absent; where there is no language barrier, absent parents alone do not influence the bond between the doctor and the child.

The differences between Sahler's study and this one may be accounted for by the registrars' maturity which leads to perceiving the child and the parents as separate individuals with different characteristics and needs.

The next topic the registrars discussed in detail pertained to communication with the parents, which included informing them about the diagnosis and prognosis as well as pre- and post death counselling. Wiener (69) in his survey of 98 paediatricians found that a larger number of doctors in practice under ten years were more prepared to give the parents an accurate diagnosis than an accurate prognosis, even when the parents asked about the prognosis. This study confirms that trend. The doctors appeared to be entirely honest about the diagnosis. However, they were very cautious about the prognosis. The registrars did not elaborate on that. Wiener points out that, "many physicians will not themselves introduce a discussion of prognosis. In some cases this may well represent the physician's judgment that parents who do not specifically ask about prognosis are not able to cope with such information" (69). Less seasoned physicians are likely to avoid discussion of prognosis because of feelings of unease, helplessness and guilt, which may be evoked by a dying child. Some registrars felt this way.

The registrars also spoke about communicating the diagnosis to the child. One registrar stressed that in his experience the parents did not want the child to be told about the seriousness of the illness and the possibility of dying, which the doctor always respected. Other registrars were not very clear about it. Even the most open families can find talking to the child about his/her own death very difficult. However, if this is a pattern to what extent should the doctor's role extend to gentle and appropriate facilitation of such communication, at least with open families? Should the families practise denial and avoidance, perhaps instead of respecting it, to the detriment of the child, the system of oblique communication could be used, wherein teachers or psychologists allow the child to ask all the questions s/he needs to (22). Respect for the parents is always highly appreciated. In the case of a dying child, at times this respect may take a form of collusion with the parents and may not always be the most beneficial to the child and his/her parents.

Another topic directly related to communication, frequently perceived as a significant difficulty, was the language barrier and need for interpreters. According to hermeneutic and constructionist approaches, language plays a part in the construction of meaning. "Language 'creates' its own reality, we negotiate reality through language. Our feelings are affected and shaped by the words we use and the vocabulary and sentence construction we have available to us. Translation in this model is a complicated matter – it involves not simply changing labels for things in the world, but also a consideration of the role language plays in determining our emotional realities" (65, p.28) An interpreter's function is thus much more than that of a dictionary. S/he often acts as a culture broker informing the doctor about the assumptions of the patient and his/her cultural background. Hence, it is understandable that the registrars often found the process of interpreting time consuming and frustrating. Some of the registrars seemed to use this process towards obtaining more cultural understanding and knowledge that was not formally provided in medical school. Some registrars felt that employing more culturally diverse professionals would alleviate the problem. Although it seems very sensible and could be helpful in many regards, it will not eradicate all the cultural problems at the institutional level (65).

Counselling and support for the parents was regarded as very important. The doctors felt that they should provide some emotional support to the parents and be aware of the need for parental spiritual support. They were of the opinion that their efforts in this respect should be complemented by the social workers and the hospital chaplain's help. Many registrars felt that they had not been able to provide adequate support. This problem was already explored in the chapter 'Teaching'.

The registrars spent substantial amount of time on discussing specific topics concerning bereaved parents. They appeared to feel overwhelmed by the intensity of parental feelings, particularly sadness, numbness, or anger. At times, they struggled with containment of these responses. This may happen because the parents project their overwhelming feelings onto the doctor, the death of some patients touches the doctor on a very personal level, and/or because the doctors have limited knowledge of grieving responses which would make such a situation more understandable and containable.

Most registrars offered an 'open door' follow-up policy. Many parents, however, did not come back, or they saw the social worker instead. Those parents that came back evoked mixed feelings in the registrars. On the one hand, they were happy to see them; on the other hand, they did not know how to respond to such a visit, what to discuss and what to say (26,33). They felt uneasy about accepting parental words of appreciation since in some way they felt guilty about the child's death. The importance of the follow up was not discussed by the registrars. It is difficult to say, whether they are not aware of it or whether there are other factors distracting them from this particular issue.

Finally, the registrars commented on parent satisfaction. Most were of the opinion that parents are satisfied with the received care. They mentioned a couple of examples where the parents were dissatisfied. In these cases the doctors felt that the problems concerned either the hospital functioning as such or resulted from parental characteristics. In order to confirm this opinion one would have to carry out a survey of parent satisfaction. Some studies show (Segal et al., 1986 in 26, 52) that as many as 60 to 80% of surveyed parents find the information or counselling inadequate, with the post death counselling being particularly insufficient. Harper and Wisian (26) report significant correlation between parent satisfaction scores and the following factors: physician's availability, providing medical information and grief counselling, with emphasis on overcoming denial. The study indicated that grief counselling was provided less frequently than any other physician action studied. In this study, grief counselling was perceived by the doctors as the most difficult part which they would rather leave to other professionals. One could hypothesise that, because of the registrars' marked uneasiness in this area, provision of parental grief counselling may be inadequate. Other factors, such as the doctor's availability and providing information may also be questionable. All registrars talked about workload and their desire to have more time "to do things properly". Because of these factors parents who are not proactive enough may not be looked after in the same way as those who are active and demanding. The issue of passive parents and cultural differences in perception of health care provision is particularly interesting and requiring further exploration. What are factors determining parental passivity? Are they intrinsic to the parents or do they result from the way the hospital operates with the doctors being a part of this system? Why do so many parents not come back for follow-up?

CONCLUSION

The doctor-parent relationship is as important as the doctor-child relationship. It is separate from the doctor-child relationship and is determined by different factors and needs. The ideal mutual doctor-parent relationship, unfortunately, is not the most frequent type developed by the registrars because of the absence or passivity of many parents and the fact that a substantial number of parents come from vastly different backgrounds. It seems that the majority of registrars are

very aware of the differences, which seldom have a negative influence on the child's treatment. The registrars do not feel confident about their counselling skills and the nature of support they provide. They appear to be fairly knowledgeable about the ways of communicating with the parents in the process of the child's dying. However, they seem to have some difficulties with counselling after the child's death. The level of cultural competence may constitute additional factor impacting on poor follow-up attendance.

RECOMMENDATIONS

The doctor-parent relationship is vital while managing the dying child. It not only benefits the dying child, but also prevents unresolved parental grief and secondary family problems at later stage. Many factors regarding parents may be unchangeable. However, one needs to understand better the factors underlying parental passivity. It is recommended that a study designed to explore this topic as well as parental satisfaction at RCCH be conducted.

The registrars need to be more aware of their role, which extends beyond the child's death. Although they may not be the sole providers of such care in the public sector, they will frequently fulfil this role as a private practitioner. Their teaching has to include the care of bereaved parents as a measure to prevent parental psychopathology, marital discord, and dysfunction of surviving children (9). The registrars could also benefit from getting acquainted with some aspects of culture relevant to the practice of medicine.

Despite tragic circumstances, the doctors can derive a lot of satisfaction from a good relationship with the parents. It is vital for the hospital management to look at the doctors' workload to enable them to be more available to the parents and to counsel them properly. Such strategy would not only increase the parental satisfaction, but also decrease bereavement complications in the family.

SECTION V

DOCTORS' PERSONAL RESPONSES WHILE FACING A DYING CHILD

Figure 5: Doctors themselves

Results

- Doctors' feelings
- Doctors' coping strategies
 - Defences
 - Instrumental coping
- Doctors' personal development

Discussion

Conclusion

Recommendations

The doctors are not immune to the impact of a dying child. Although the loss of a patient is not comparable with the doctor's personal losses, doctors being in the middle of very anxiety provoking situations are frequently the recipients of parental emotions and projections from other staff members. Coping with these feelings may not always be easy and may lead to the development of specific unconscious and conscious defences. Some of these result in enhanced coping strategies that benefit both the doctor and the patient; others may be to their mutual disadvantage.

Figure 5 includes a comprehensive list of the registrars' feelings, conscious and unconscious ways of coping evoked by a dying patient imbedded in a broader context. 'Circumstances' in the figure refer to the dying patient's family and the hospital. The doctor's personality coupled with an ongoing personal development influences the nature of feelings s/he experiences as well as his/her coping styles which, in turn, impact on treatment of dying patients in the future

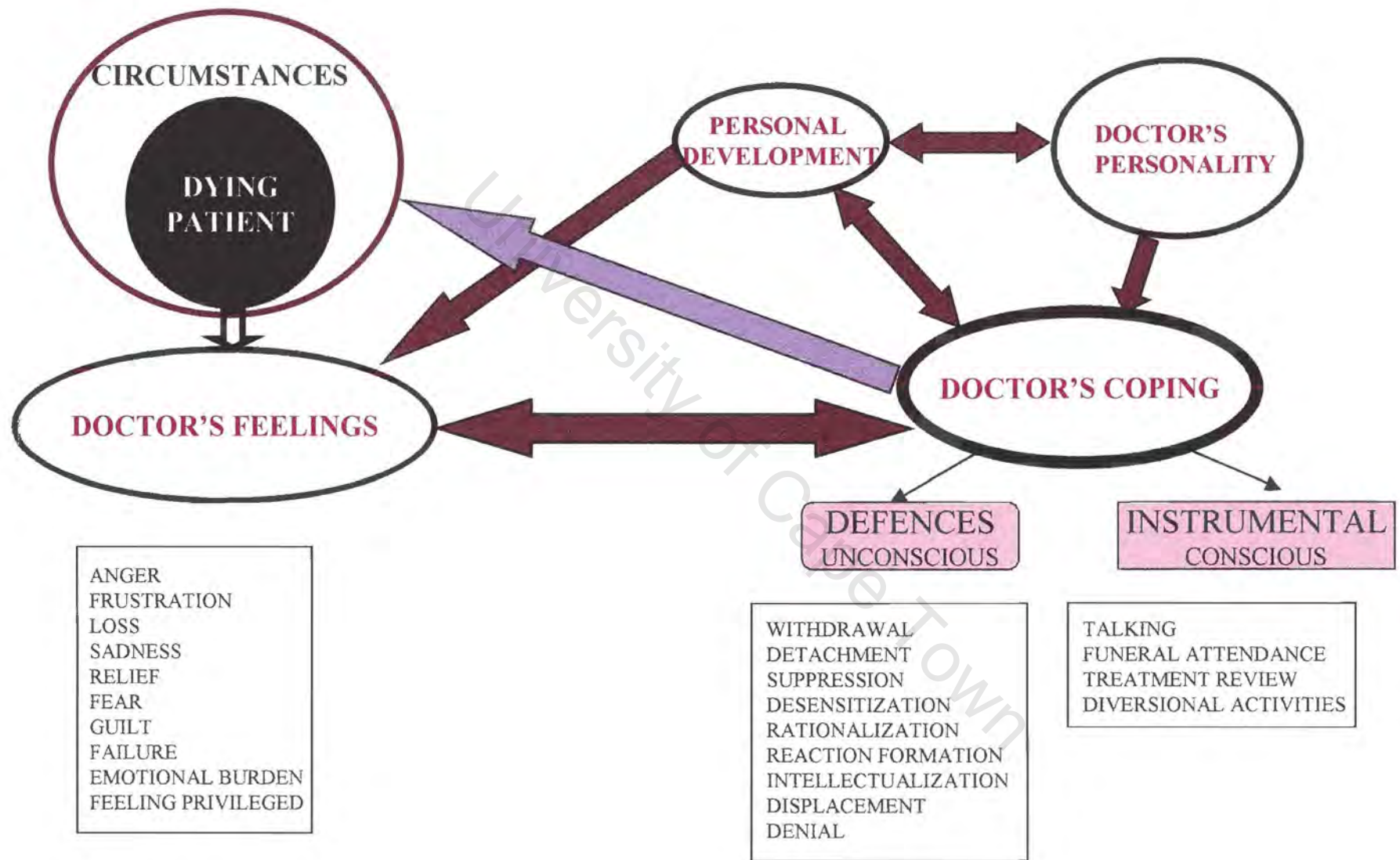


Fig 5: DOCTORS THEMSELVES

DOCTORS' FEELINGS

Dying and death of a child is always difficult to accept. This is a stressful event impacting on everyone in contact with the child, including medical professionals. The process of dying and death of the child evoked a wide range of feelings among the registrars.

ANGER

The child's suffering and death seem to be unfair and deprived of any logic and meaning. Such death evokes anger with God, with consultants who make decisions about the withdrawal of active treatment. A great amount of anger is directed at the institution, which due to financial constraints is not able to provide the best treatment possible. The doctors tend to get angry at the socio-economic situation of the country that impacts on the availability of services. Finally, doctors experience angry feelings with themselves for not being able to prolong life and improve the quality of it.

- Anger is also a big thing. Why do children die? - you ask it all the time. Why does this little girl who's gorgeous, who's got a nice smile, who comes from a nice background, why does she have to get cancer, or why does she have to get chronic renal failure, or whatever. Why did they have to get that problem and why do they die? And yet, you've got these crummy old people who've smoked and drunk and been absolutely terrible people all their lives, and they're still alive, aged 92; just it's not fair. You get angry in that respect. You also get angry because if we had more money in this country, if we had better services and a bigger ICU, we could transplant more patients. This child wouldn't have died. The child would still be alive if the mother had a job, and the father had a job, and the social circumstances were better. If dad wasn't sleeping with twelve women and given his wife HIV, the child wouldn't have been dying of HIV. So, now you get angry with him, and you get angry with the state, and you get angry with God or whoever you believe in, because they are not playing the game. If someone dies aged 92 of a quiet stroke, you think: "Hey, good life", but when you're two and a half and things are looking good and you get hit by a car or you get some terrible disease, you just think: "That's not fair, it really isn't fair".
- The consultant came and told me (about the withdrawal of active treatment). I remember not being able to say anything, but just thinking: "How could they make that decision that they couldn't do anything further for this child".
- There's nothing more you can do about it to influence that (death). So, whether you feel sad, you feel depressed, you manage a bit of anger as well. On the one hand, anger that he was called on to go home and on the other hand, anger that from a medical point of view your inability to do anything to prolong his life or to improve the quality of his life.

FRUSTRATION

Some doctors become frustrated rather than angry. This feeling mainly pertains to a lack of medical infrastructure and resources, particularly at the primary and secondary level, where the doctors' skills could have been used if the hospital was better equipped.

- There's nothing else that one could realistically do in that situation (a child dying of respiratory failure because of lack of facilities). But if one was in a different situation, one could have done more. Because one had the skills to do more, I guess, it is the frustration.
- It's a national system, the national system that didn't provide for the child presenting with a respiratory failure after hours. If it had happened in daytime hours, we could have flown that child out. But the airstrip was grass with cows on it. So, you can't fly in there, you can't find it at night. You know, it's not that sort of airstrip.

EMOTIONAL BURDEN

Looking after chronically ill patients and multiple losses of patients lead to an emotional burden, which may be aggravated by the issues of responsibility of decision-making.

- In that particular case we did have quite a lot of discussion. It was helpful. But there were other cases where it didn't happen. It's not just the issues of responsibility, it's the burden, the emotional of burden of looking after those patients.

SADNESS/ LOSS/ GRIEF

Doctors bond with their chronically ill patients. Their loss triggers feelings of sadness and grief responses whose depth depends on the quality of patient/parent-doctor relationship. These feelings are, however, less profound than when experiencing personal losses. Sadness arises when doctors realize their limitations and inadequacies in the face of the more powerful laws of nature.

- My sense of grief was related to my ability to bond with the child over time and identify with the mother. I bonded with the mother too.
- It's always sad to lose a patient.

- I'm pleased if they get better, but if they don't get better, it's not that I'm not sad, but I'm not as sad as I would be if I was the relative or parent or close friend. It's a different kind of sadness.
- It's sadder in some respects when they (older children/teenagers) have got somewhere, they've achieved, they're doing, they're at school, they relate to you and to other people, and then they die. The little kids, it's just the beginning, and if it wasn't meant to be, it wasn't meant to be. I know it sounds terrible. If God's gonna make a decision that this person's not to live or is to die then, we as doctors are kind of fighting something bigger than ourselves in many respects. I don't know if it's God's decision or what's the decision, but someone's making the decision about these kids that's beyond us. Genes, bad genes. You know what I mean.

RELIEF

The patient's death is experienced as a relief only when the child's condition was accompanied by long standing suffering and very poor quality of life.

- In many ways as with a lot of chronic illnesses, the relief (after a child's death) was the major feeling.
- Sometimes it's a relief, maybe it's because the child's got a terminal disease and suffers. Maybe that's a way of thinking of it. Maybe that's a wrong way. The child is now in heaven, and a lot of people think of death as a morbid condition. Maybe it's relief and no one knows what heaven is about, maybe there's a better life after death, especially for the children in neurology. A lot of them are disabled; a lot of them don't have a good quality of life, especially if there's been suffering.

SURVIVOR GUILT/ GUILT

After a child's death some doctors experience short-term survivor guilt. They feel uncomfortable about pursuing pleasurable activities soon after their patient's death. They tend to analyse the course of events leading to the child's death and feel guilty about not carrying out procedures that they think might have saved the child's life.

- The survivor guilt - you get that feeling also when you're a doctor. Here I am trying to resus this baby and I'm failing, and yet I get to walk away from this, I get to go home for supper and watch some TV tonight, and this child is dead now. There's a lot of anger in a lot of directions. There's a bit of guilt in respect of "I'm alive" and in respect of "Did I do enough?" and "Hell man, if I got the tumor earlier" or "Maybe I should have tried some calcium gluconate". These things run through your mind, you analyze, and you go back, and you think: "Oh sure, maybe that was ideal".

- One or two patients, that's probably been most traumatic to myself, have been patients that have died because of maybe failures of my own method or a misdiagnosis.

Guilt is not experienced if the child's death is anticipated and follows the administration of all possible treatments.

- After all the medical treatment we tried, eventually she died peacefully at home. That's the way it is. There's no guilt there. We tried our best. We did everything we could and that's great. The whole thing is sad that the child had died, but there's no guilt, no anger and it was actually quite peaceful.

FAILURE

The doctors are part of a health system. The sense of failure arises when the system fails, e.g., impaired communication among health care professionals, unavailable services, or diffused responsibility.

- It's often less than me - the individual - that's failed. It's me as part of the system that's failed. The system has failed this child. If only the lines of communication were better and this patient was referred two days earlier. So, the system has let the patient down and I'm part of the system. Can't I make it better?
- In the setting, in which we work, there isn't actually a lot of personal responsibility held. You're not used to having to justify decisions to parents or to other doctors or to a court of law. When you work in another country you become much more aware of that. It's an area that's developing. At the moment when mistakes are made it tends to either be covered up or individuals take home a sense of responsibility about it. They feel terrible or they get pinpointed themselves. In fact, what it reflects is a problem with the system. Either people are working too long hours, or something isn't being checked by somebody else, or a medicine is being confused with another medicine because of the way they were packaged, or something like that. It's not really the personal failure. It's a system failure.

Doctors seem to be fairly confident about their medical skills. Thus, death of a patient seldom evokes a sense of personal failure, although many doctors ask themselves the question: "Have I done everything?"

- Occasionally you think: "If only I had done X or I hadn't done Y, why did I put the patient on this drug, look what happened to the kidneys, or look what happened to whatever"

FEAR

There is a feeling of apprehension and fear that the death of a child may strike again. Death of a patient also evokes anxieties and fears related to one's own mortality.

- The fear of it happening again - that's always a concern. If you have a bad experience, you don't want it to happen again. In a professional sense it's inevitable. Doctors sort of throw away lives like it was the only thing. What's absolutely definable and diagnosable is death. It's the only thing that we really dread.

FEELING OF BEING PRIVILEGED

A relationship with a chronically ill child, who has been strong in his/her terminal fight as well as accepting things happening to him/her, has a very special and intimate quality and is highly appreciated by doctors. It is a privilege to witness and share the patient's suffering.

- There's much of a reward in a chronic death for you and more of a privilege to be involved with.

DOCTORS' COPING STRATEGIES

DEFENCES

EMOTIONAL DETACHMENT

The meaning of detachment was described by the doctors as emotional distance maintained while treating a dying patient and his/her family. This distance was graded from relatively detached (what one could call mild detachment) to totally detached.

Mild detachment is perceived as healthy and constructive at the level of decision-making. It helps the doctor to assess the patient's condition more objectively and implement the most appropriate treatment. The doctor is able to strike a balance between seeing his/her patient as a person and as a biological entity.

- There are people who distance themselves completely from their patients, people who have to make decisions about life and death. They don't want to know their patients on a personal level, which is incredibly sad because then their job becomes impossible.
- I did find during that block (oncology), I specifically made a point of not getting very involved, and in some cases it's much easier if the patient's of a very different social class. It's easier not to get involved. It's not easy in terms of trying to explain the severity of the problem to them if your patients and parents of your patient don't speak the same language. But I found those patients that I would relate to socially, if I happened to be in hospital with them, I'd have to make a conscious effort not to get very involved in them, but that's very few patients.

- I make sure I don't get too involved with my patients. I still do talk to the mothers and I am supportive.

Not getting involved with a patient protects a doctor from feeling bad about a very sad and, at times, unbearable situation. It decreases the emotional burden and prevents early burnout.

- I don't need to be emotionally involved in them to see them getting better. It's the end of an equation and there's a significant number who don't get better. So, if one got involved, if the end result was gonna be that they get better, therefore I get happy, then I'd be sad a whole lot of time. Maybe it's a subconscious thing, a protective mechanism from feeling bad about the situation.

Some doctors, particularly those who have been exposed to a lot of dying before, or whose relationship with parents has been tense, make a conscious effort to block off any sad feelings and to detach from the start. It may take the form of a physical withdrawal, e.g., avoiding any contact with the patient and his/her family other than what is absolutely necessary or letting them know about how busy the doctor is.

- I became detached, I think, early on because of my first job where there's a lot of death there, generally more acute death, because the patients arrive having been chronically ill for a long time at home. They come and die a few days later in hospital. I would say I developed quite a thick skin to death and dying from early on.
- Remaining detached means you can spread yourself evenly. For an individual it would be, I guess, more to their benefit to have more time from any one doctor and to talk about it (dying) more if I could tell them useful thing. But I don't think I always can. So, I think it's much to their disadvantage that I'm a little bit detached.
- It depends on your relationship with the parents. If you know the parents very well, if you're very involved that (detachment) does not happen, you may feel deep feelings for the parents. If you don't know the parents at all, if they perceive you negatively and they don't accept the situation, you may actually want to withdraw, particularly when the relationship with the parents is very stressed.
- Most of the time the parents realize that you're busy, but they'll only realize that I'm busy if I let them know that I'm busy. For example, if I come in and say: "Right, you know, I can talk to you all day", then they will, just anecdotally. But those that I get more and more involved in, it's just easier for the conversations to get longer and longer, and the issues to get broader and broader.
- It's not easy to get into those discussions. It's not an easy discussion to have, but it's a situation which occurs more frequently if you got more involved in the patients

DESENSITIZATION

Detachment is frequently preceded by desensitisation or hardening, as many doctors put it. Desensitisation tends to occur when the amount of work trauma exceeds the doctor's capacity to process it. It is perceived by the doctors as being internally less sensitive to the patient's suffering and death. On the surface, the doctor may still appear as compassionate as before and interact with a patient well.

Desensitisation is regarded by the doctors as having a potentially negative effect on the patient. On the other hand, it is viewed as an important mechanism protecting them from burnout. It also enables them to continue performing their medical duties.

- You start having a thick skin, it happens. You get desensitised if it happens enough. I'm sure, if I go back to England, and I worked there where's maybe one death every six months, maybe then it's more difficult for me to deal with it. When you manage one of our medical wards, where you physically have one or two children die and you get a red-box once or two in a week, then you become desensitised to it. I think it's probably a protective mechanism because if you are going to get emotionally involved, which you see in some of the junior doctor or the junior staff, they cry and they become upset, and if you go through that phase, you're gonna have emotional burnout. You take the world on your shoulders. I don't think it's when you're gonna function properly. I think you have to detach yourself. It may not sound like the right thing to do
- You have to harden yourself because it happens frequently and you can't keep all the burdens of every patient you ever lost inside you. I think you probably do, but you tuck them at the back somewhere.

RATIONALIZATION

Rationalization is broadly understood as trying to explain certain outcomes, particularly when some processes are beyond the doctor's control. It tends to be employed while making end-of-life decisions. This mechanism serves to justify treatment decisions, particularly in patients with very poor quality of life. There is a lot of post-mortem rationalization, which helps to cope with feelings of guilt and emotional burden.

- The first way of dealing with it (issues around death and dying) is probably rationalisation. Somebody else could have done the same thing, or it wasn't me, or it's the disease, the child shouldn't have been born like this in the first place, or just rationalising it, and the rest is time. It just goes away with time.
- I'm sort of able to rationalise. My function is to look after the quality of the child's life and to be there for the parents, not just the medical aspect, but also the emotional aspect and the supportive aspect. It's frustrating sometimes, seeing a small child becoming weaker and weaker and weaker, and there's nothing you can do about it.

REACTION FORMATION

Reaction formation refers to doctors' actions that are of a compensatory nature. Doctors try to make a child's life more bearable while in hospital. They tend to buy things for the children, from sweets to toys, to clothes. They give them extra hugs. They take them out on weekends. A special effort is directed particularly at those suffering most and those who seem to be abandoned by their families. Such activities seem to ease doctors' pain and provide them with a sense of doing everything possible for the child.

- You want to give a little more to this child. If they want a Play Station, you go out and buy the Play Station. There're patients like that on the ward. You spoil them. You try and make what little life they've got as good as they can. You do spoil them to a limited extent. You buy them sweets, and you buy them chips, or you give them some cash, and you give them the extra hugs, and stuff. But it's also because the relationship's got to a point where you're sharing anyway.
- Because he didn't have his mom with him and he hadn't bonded well with his grandparents, he spent most of his time in the ward actually. The two of us became particularly close in that I would visit him on weekends and take him out.
- It's just lovely to be with them. They're lovely children. A lot of them have not done things or seen things. I often take children out for things that they've not done or that they'd like to do. I just enjoy doing it.

SUPPRESSION

Suppression relates to a process of forgetting about an unpleasant situation. Discomfort is acknowledged but minimized. Some doctors try not to think about the death of a patient. Others, after a short analysis of the events leading to death and ascertaining that they were not at fault, will forget about it.

- I don't think about it. I don't go out there to deal with it. You just go out, you exercise, and you forget. You have to forget. And then your wife says to you: "But tell me about it now, what really happened?" Then you think: "Oh hell, that happened". Then maybe you mention it, but you tend not to.
- If the patient died and no one that I know that was present was at fault, it was more of a natural death, then I will accept it and move forward. If I think that someone, myself or others, were at fault, then it will trickle around in the back of my mind for about a week and then it's gone.

REPRESSION

Repression refers to feelings that are expelled from consciousness leading to blockage of the conscious perception of feelings.

- I actively, after that week's gone, I don't think about it any more (death of a child). It's gone. Whether it's actually passive, it's difficult to say. That's why I struggle to remember specific instances.

Some employ repression so well that they remember dying patients as a group, not as individuals.

- So, patients that I was involved with may well have died, but there's no patient who I feel that I remember specifically, who I've been very involved in in a long chronic drawn out thing, and then they've died. There's a group of patients, which is predominantly patients with chronic infectious diseases such as HIV babies who come in, but I can remember them as a group I don't remember them as individuals.

DISPLACEMENT

As stated above, the process of dying and death evokes a great range of feelings. Some of them, particularly those of a more negative nature, e.g., anger, may not be processed easily and are displaced onto someone else. Irritability towards the doctor's family was mentioned by some of the registrars.

- An unavoidable death is something that happens a lot. It does affect me where there's been a lot of emotional hype or where there's a lot of upset parents in there, something big has happened. I will be more withdrawn at home for a while. I will be maybe more irritated, more grumpy. I could be more anything. It would affect my mood for a while, maybe for a day or two if it's a serious thing, but I will try not to let it, I guess, because it's not nice to be irritable and grumpy. Usually I'll fail anyway, and then I go out.
- The major person who dealt with it really was my spouse more than anybody else. My spouse got it all when I got home. I was told by my spouse: "You look very miserable", and it's exactly what it is.

INTELLECTUALIZATION

This defence mechanism emphasizes excessive use of intellectual processes. Attention is paid to the external reality to avoid perceiving the whole and to avoid the experience of inner feelings.

- I've always liked to look for that child that still managed to pull through because we've all seen it happen before in terribly sick children. I always sort of quote the figures and say: "If you've got a multi-system organ failure

and you've got more than five organs, your chances are less than 10%, so just bear that in mind". I just say:" Well, so her chances are only 4%, but still you know, that's still 4%, and if she gets through this, she'll be fine. Another night and she'll be okay". Not sort of like so simplistically, but so I maybe think sometimes that, especially when they're that sick already, that just adding on the thing is not gonna make their life so much worse, whereas it could actually be the right thing that the child gets better, that's providing that they still look comfortable.

DENIAL

Denial of the patient's condition may occur during the early phase of the registrar training when doctors are relatively inexperienced.

- I remember very vividly my feelings on hearing he had relapsed again and, I think, probably partially because of my in-experience at the time, and partially because I really was so fond of that little boy. The head of department was his primary physician, and I was really angry with her at the decision that they were not gonna go for any further treatment. I was so desperate to save him. He was just the most angelic little boy and I couldn't believe that would mean that by the end of the month he would be dead.

Denial is seldom employed at the later stages of medical training. It may present as a short-lived constructive response enabling a doctor to diagnose an illness and consider all treatment options.

- It's very different with different patients. Maybe if you are more involved with a child for a long time and you're planning the surgery and other procedures it might be denial.
- Sometimes you get a child where in the flare of activities you've got to investigate them and treat them, and do something about them. It is (denial) in that sense.
- Denial is actually coping. At resuscitation perhaps you function like that.
- No denial. You feel sad, sad about it, but to deny?
- I don't think we deny the illness.
- They're often for years in that situation. You don't break down. You deal with it. But there is a great difference between the child you are involved with and the child you are not familiar with. But there comes death in pediatrics very often. It is not a surprise or shock.

ACCEPTANCE

Acceptance of the process of dying, although difficult, seems to be a prerequisite for patient's comfort in his/her final stage of life.

- You have to accept death on a professional level. But if you can't accept it, you can't practise medicine.
- You can make people comfortable. You can do your best for them, and at the end you can accept that it's the end, and you can let them go gracefully

INSTRUMENTAL COPING

Instrumental coping refers to conscious efforts employed by the doctors in order to cope with a stressful situation. The most frequently used strategies are treatment review, diversional activities, attending funerals and talking to others.

TREATMENT REVIEW

All the doctors apply this strategy after a patient's death. It may range from rethinking the whole management process, going through the notes and checking whether everything was done, searching through "Nelson" in order to reassure oneself that the administered treatment was appropriate and adequate, to discussing certain details with colleagues. This thinking and checking may range in duration depending on a nature of involvement with the patient.

- I'm quite a perfectionist. Everything is to be done in a certain way and certainly the way I treat the patients has to be done in a certain way. In every child that dies I would always go through the folder and check that everything was done absolutely perfectly; and if I didn't, I would think about that one thing that I didn't do over and over and over again.
- But you go back to the textbooks that night, you'll look it up and you say: "Well, here it is in black and white, in the bible of paediatrics. Nelson would have done the same thing and I did it", and you feel justified that your actions were not part of the death of the child.

DIVERSIONAL ACTIVITIES

To cope better with the unpleasantness of the situation several doctors actively pursue some activities enabling them to 'switch off'. They mentioned going for walks, taking the dog out, running, or hiking. These strategies seem to work only to a certain degree.

- I'm getting better at going for walks, or taking the dog out, or doing stuff to get my head around certain things.
- I'm pretty active, mountain walking, etc. I do other things each time which take my mind off dying. I do high-risk sports, so it probably helps. I've got ways of escaping from work. I always wonder why people do that. It's probably a way of getting away from the stress of work. I'm not sure.
- You get home in the evening. You're tired from a busy day. And if someone died, you put on your shoes and you run. You don't think about it.

ATTENDING THE FUNERAL

The funeral of the patient is perceived by some registrars as a catharsis and closure. It facilitates doctors' grieving process. Several registrars, who had developed a close relationship with their patients, expressed their willingness to attend the funeral.

- Occasionally we go to funerals of children that we've known very well. I've been to two. The whole team went to one child's funeral. She spent about three weeks in intensive care. We built up a very good relationship with the parents who were there all the time. So, all of us went to the funeral. That's a good way of closing. We don't do that for most of the children.
- A funeral - it's a catharsis, I suppose. That's what it's designed to do. Nobody's designed it. That's a process. To do that brings things closed. It's probably helped the doctors as much as it helped the family. In fact, the family asked us to be pallbearers at the one funeral which showed that they still respected us, although she died.

TALKING TO OTHERS

Most doctors felt the need to talk to somebody about a child who died. The ways the registrars obtain support will be discussed in detail in the chapter "Emotional Support for Doctors".

DOCTOR'S PERSONAL DEVELOPMENT

Many doctors have grown through their patients who allow them to see a positive aspect in the process of dying and death. It is their very young patients who have made them appreciate their good fortune, realize their own limitations and mortality, experience the depth of feelings when a child dies, and remain strong even in a face of the most tragic events.

- (Death of a child) It makes you appreciate the things that you have in life more when you're exposed to the misery and suffering.
- You feel depressed about it and sad about it (death of the child). One thing that comes to mind is that my feeling is that everyone in life gets dealt a hand of cards and some people are just very fortunate to be brought up in good, caring families with no financial problems, with good health, and other people have just been dealt a bad hand of cards. Parents are not caring; parents are separating, with a chronic illness.
- I think of death as sort of being scared of it and thinking: "No, this is not the worse". One knows what death entails and maybe there's a better world for us than this one
- I don't think that prior to that (dealing with a child resembling F's daughter) I've ever tremendously considered very much about my own mortality. It was perhaps a growing experience in a sense of reflection and recollection. I am gonna die one day and I have to face it. I have to face the reality.
- That's an incredible privilege to see some of these children who fight till the bitter end. It gives you enormous courage in your life and also awareness that under the worst circumstances people can still smile, they can still give you the time of day and be happy, and yet other people sit and moan about the smallest things in life.
- Life's too short to dwell on bad times and sad times. You've gotta get on with things and so on a personal level things should be done in such a way. It's not just a professional belief. It's kind of a personal belief.

DISCUSSION

Doctors facing a child suffering from a chronic fatal illness experience a wide range of feelings, which are compatible with E. Kubler-Ross's responses to impending death as well as the grief reactions.

Kubler-Ross (34) distinguished five emotional reactions that mark the psychological response to dying. They are denial, anger, bargaining, depression and acceptance. This study seems to show that the doctors, who come into contact with a dying child, experience the same pattern of responses.

Denial. It was the least cited response by the registrars. One registrar mentioned it in terms of disbelief and shock at the very early stages of registrarship. Denial may not be a usual response because of the nature of the medical profession, which is accustomed to and defended against 'shocking' and life-threatening diagnoses.

Anger. When denial can no longer be maintained, it is often replaced by feelings of anger and frustration. The doctor, similar to the patient or the patient's parents, asks the question: "Why does s/he have to die? Why do I have to lose the patient?" Anger may be displaced or projected. It appears that doctors tend to displace it on their consultants and on their families. They project it onto God, the patients' parents, and the hospital system, which is embedded in a broader national context.

Bargaining. This is an attempt to postpone the inevitable. Although only one registrar referred to bargaining, certain examples of the situations in which the registrars participated indicate that bargaining takes place in the hospital and presents as excessive and prolonged treatment that does not alter the final outcome. It seems that doctors may tacitly collude with parents in this regard or undergo this process because of fear of professional failure.

Depression Many doctors reported a sense of sadness and loss, particularly when they developed a close bond with the patient and his/her parents. Similar to patients or their parents, registrars experienced two types of depression: reactive and preparatory.

Reactive depression results from the registrars observing the losses in the patient's functioning and the loss of the potential that the patient would otherwise have had. Another powerful reason for reactive depression is the registrars' identification with the parents and their feelings. Finally, this type of depression results from the registrar's loss of control over the process of illness and the painful realization of his/her limitations and inadequacies.

Preparatory depression refers to grieving over the patient's impending death and may be compared with anticipatory grief, which is expressed in advance of a loss perceived as inevitable. Once the registrars realized the finality of the outcome and their inability to offer any further active treatment, the feelings of sadness, helplessness and hopelessness ensued. It is important to note, however, that most of these feelings are less deep than in the case of the doctors' personal losses. The registrars gave two explanations for it. 1) The attachment and bonds with their own families are much stronger than with their patients. 2) The doctors perceive themselves as having more control over their patient's illness than over that of their own family members'.

Acceptance. According to Kubler-Ross, acceptance refers to a stage in which the dying individual will contemplate his/her end with a certain degree of quiet expectation. The struggle is ended. The registrars appear to have reached this stage, particularly in cases of long standing illnesses, like cystic fibrosis or muscular dystrophies.

All the above stages may be induced by a mixture of the patients' and the parents' projections and doctors' own anxieties related to death and dying (36).

What happens with the doctors when the patient, with whom they had a close long- term relationship, dies?

GRIEF is the subjective feeling precipitated by a loss. Uncomplicated grief is viewed as a normal response. It consists of three phases: shock, preoccupation with the deceased, and resolution (31). These phases are expressed in feelings, thoughts, and somatic symptoms of the bereaved person.

Shock. The initial grief response manifested as a state of shock, numbness or a state of bewilderment, is usually short lived. It seems that the doctors seldom experienced this phase. When they did, it usually occurred at the beginning of their professional career when they lacked clinical experience, which may have influenced their judgment. Most doctors perceived themselves as being fairly realistic about the patient's prognosis, despite the many hopes and wishes that they may have held.

Preoccupation with the deceased. This is the second phase of grief in which the bereaved may experience anger, sadness, survival guilt, failure, self-reproach, and anhedonia. Somatic symptoms, like anorexia, insomnia, weakness and fatigue may accompany thoughts about the deceased.

All of the registrars appear to have gone through this phase. They experienced all the above feelings. Since anger is an externalising feeling, its expression may well serve as a defence mechanism protecting the doctor from the overwhelming impact of internalising feelings, like e.g., depression that could impact on the doctor's clinical performance.

Other emotions, like sadness, failure, survivor guilt were reported as far less profound and rather short lived. This phenomenon could be explained by anticipatory grief that the doctors usually have an opportunity to go through. Anticipatory grief ends with the occurrence of the anticipated loss, regardless of what reactions follow. These reactions may decrease in intensity soon after the patient's death since the major grief work had been done before the patient's death.

The registrars seldom experienced a sense of personal failure so frequently cited in the literature, as a common feeling in doctors dealing with a dying patient (9,32,34,53,58). There may be several reasons for that. The doctors work in a tertiary hospital where supervision and advice are easily obtainable, if necessary. Most doctors were in their mid thirties having had approximately 9 years of experience, which is reflected in their confidence as far as clinical skills are concerned. Finally, they seem to maintain very realistic expectations of the patient suffering from a chronic fatal illness and pay attention not only to the prolongation of life, but also to the quality of life.

Somatic symptoms were not reported by the doctors during this phase.

Resolution. The phase of resolution and reorganization follows when the bereaved person recognizes that his/her life will continue with new adjustments and different goals. Three key factors affect the resolution process: (1) the degree to

which the person acknowledges the reality of what has happened, (2) the flexibility and the effectiveness of the person's coping skills, and (3) the availability of support and the willingness to use it (31)

The registrars acknowledged the severity of the patient's condition. On most occasions they did not experience problems with recognizing a downhill course of the illness and the impending death of the patient.

They employed a vast array of mature defences (31), which are healthy and adaptive in adult life, like mild emotional detachment, altruism with its benign and constructive reaction formation, and suppression.

Defences, such as displacement, rationalization, repression, and intellectualization are encountered in adults under stress. These are employed by the registrars since the process of dying and death belongs to one of the more stressful experiences in hospital.

Excessive detachment and desensitization as well as excessive identification with the parents, which becomes an entrenched pattern, may be detrimental to both the patient/parent and the doctor.

The registrars demonstrated effective coping skills. They used treatment review to ward off feelings of guilt. They attended funerals, if possible, which by some were perceived as a final closure. They distracted themselves from preoccupation about their patients by emerging themselves in diversional activities. Finally, most of them accessed support of their colleagues or families, if they were in need of doing so.

The doctors' grief resolution may be hampered by the excessive number of dying children, which is clearly visible in a discussion around AIDS. In this case doctors may not have enough time to readjust to their new goals of dedicating themselves and enjoying satisfaction of treating the children with a good prognosis. When death strikes repeatedly, the registrars have very little space for deriving satisfaction from other aspects of their work. Inability to offer active treatment leaves the doctors with a sense of helplessness and a diminishing belief in their "curing" abilities, which may lead to professional burnout.

The registrars also noted that death of a patient, with whom they had a close long-term meaningful relationship, might provide them with additional strength and contribute to their personal development. In this regard, they echoed Kubler-Ross's words who considered death as the final stage of growth (36).

CONCLUSION

It is evident that doctors experience the same range of reactions and feelings to dying and death as their patients or their patients' parents. The intensity of these emotions depends on the closeness of the relationship between the doctor and the patient/ the patient's parent, which is lesser than in the case of the doctor's personal losses. While dealing with death and dying, the registrars employ mature defence mechanisms and flexible coping styles, which contribute to a positive resolution of their grief. Some registrars, who have negative experiences of death and dying particularly at the beginning

of their professional career, may be at risk of employing defences which impair the quality of their relationship with the patient and prevent them from deriving more satisfaction from their work. The grief resolution may be impeded by the large number of dying children. The physicians may not be able to process these events in a short period of time.

RECOMMENDATIONS

Establishing structured support for doctors would enable them to manage their feelings more effectively. The doctors' perception of not being able to do anything in the final stages of dying deprives them of deriving satisfaction from providing end-of-life care. Thus, it seems of utmost importance that the reality of a dying patient and death should find an equal place to cure and prolonging life in the science of medicine. Only then will the doctor find his/her work with the dying patients meaningful and valuable. This needs to be supported by doctors at all levels of their professional advancement in order to prevent dysfunctional ways of coping, which junior doctors may develop.

SECTION VI

EMOTIONAL SUPPORT FOR DOCTORS

Figure 6: Emotional support

Results

- Hospital stressors
- The existing support structure
- The quality of support
 - Family
 - Colleagues
 - Consultants
- Suggested support
 - Regular debriefing sessions
 - “Ad hoc” support groups
 - Individual counselling sessions

Discussion

Conclusion

Recommendations

Doctors have to deal with multiple stressors in hospital. They are often expected to support their patients and the nursing staff. There is an expectation that the senior physicians should provide some support for junior ones. It does not seem to happen, though. This study as well as the literature seems to confirm the fact that the doctors constitute a professional group who are the least supported among health practitioners.

Figure 6 illustrates three sources of support for the registrars: their families, colleagues and consultants and points out towards the doctors' ideas about a more efficient support structure.

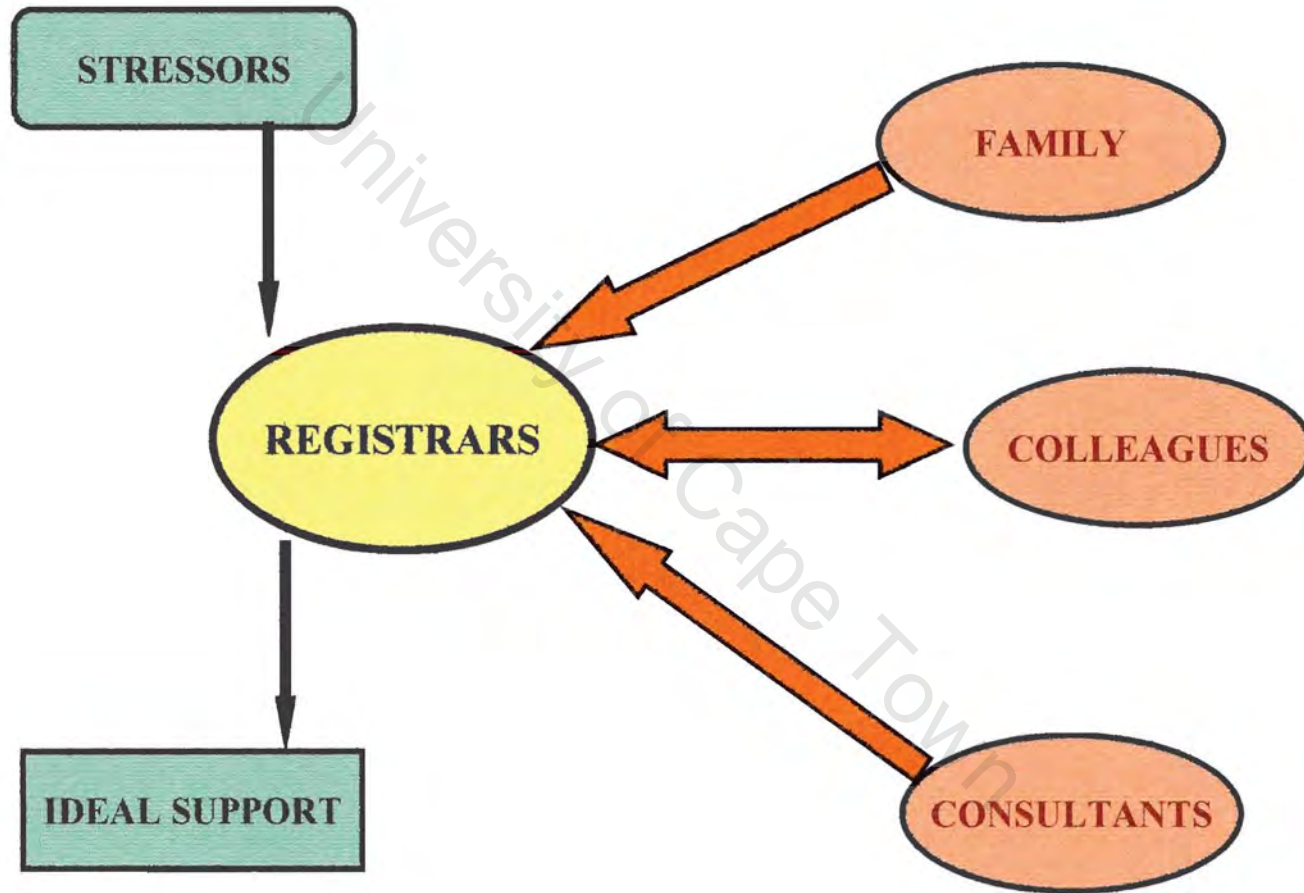


Fig 6: EMOTIONAL SUPPORT

HOSPITAL STRESSORS

Several registrars emphasized that the death of a child does not belong to the most stressful events in the hospital life. What may be difficult to manage are the circumstances surrounding the process of dying: interactions with the children themselves, their parents, other staff members, decision-making, workload, physical exhaustion, cultural differences and the economic situation, both at the hospital and the national level.

- It's very seldom that my source of emotions, ironically, is purely as a result of the death of a patient. It's as result of circumstances. It's seldom that the death of a child is what is really the big tragedy in terminally ill, chronically ill.
- In my latest experience, the mother cried and cried and cried for an hour and a half, and for half an hour I sat with her. You can't sit with her forever. You've got to get on. Again, it's time constraints. Now I've got clinics to go to and I've got other patients to see to. You don't have the time to sit and spend time with them, so you spend twenty minutes, half an hour.
- I find it very difficult if I have to work through a translator. I find it extremely difficult. It's very frustrating.

THE EXISTING SUPPORT STRUCTURE

Most doctors tended to talk about two kinds of support. Firstly, a clinical one, relating to treatment decisions involving complicated ethical dilemmas, and secondly, the emotional support.

The registrars were fairly satisfied with the amount of clinical input, supervision, and clinical support.

- At Red Cross the support is there. Generally, there is other people who will say that we agree with you or we disagree with you, and then there's forums for discussion, and that's important. There's ethics meetings here at least once a month to present kind of cases like that.

The registrars are not aware of any formal emotional support structure. They emphasized the importance of the availability of support not only in terms of dealing with a dying child, but also in terms of daily stress that each doctor has to cope with.

- The whole medical thing is a big stress in itself and doctors get just as involved with the patients as certain sisters do. Who can the doctors talk to? Nobody.
- There's certainly inadequate backup for senior registrars, consultants, junior consultants, SHO's for getting that kind of thing out (talking about dying children). It should be got out because otherwise it's a burden that leaves with you.

- Being in the ICU, you've got no set up at all, neither for nurses nor for doctors which is completely inappropriate. There's nothing in G1-in the oncology ward, like a support group or just a chance once a month to talk about a patient.
- In the oncology ward and the ICU the doctors are actually primarily responsible for the patients and have other stresses to deal with because they have to deal with the nurses as well as the parents.

It is interesting that some of the registrars could refer to structured support while facing death in a non-hospital setting, where such a situation occurs relatively sporadically.

- The formal thing is to actually go and speak to somebody and there's no such thing in the hospital. I was also involved in mountain rescue. We had a period where there was about five deaths. We got counselling, and a psychologist came and counselled the people about it, especially the people that actually went to pick up the bodies. We thought of actually doing something like that for the doctors, but that hasn't happened yet. Doctors are supposed to be able to cope with it.

THE QUALITY OF SUPPORT

In order to obtain some informal emotional support the registrars try to approach three groups: family, colleagues, usually fellow registrars, and consultants.

FAMILY

Those doctors who are married to medical professionals talk to their spouses about both the clinical as well as the psychological aspect related to the management of a dying child and his/her death. They seem to be understood by their spouses, which seems to facilitate grieving and brings some relief. Those registrars who are married to non-medical spouses or who are not married, tend to discuss only selected aspects with their families or nothing at all.

- In the other case (where F identified with the child's parent), it was feelings of grief. There was a sense of loss of my own, and in that instance it was more talking to my wife about that.
- When, I think, I made a mistake my spouse will know about that and will hear it over and over again.
- It helps in a sense that she's medical 'cos she understands the setting, but it usually gets off that quite quickly because that's not really the issue. There are frustrations about the pure medical management of the patient or whatever, but it's more the sort of feelings it gives rise to. It doesn't go the whole way at times, but it's difficult for the partner sometimes.
- You lose a patient and everyone says: "Ah, not to worry man, it was for the best, you did your best and don't worry", and that's it. No one else would sit down with you and say: "How do you feel about it?" I think it's bad not to take it home and speak to someone about it, but at the same time you can't burden your partner with the problems that you've got.

- I don't talk much, but if it is personality clashes and sort of social issues, and there's plenty of those, just to keep conversation going, it's nice to have a sounding board. The medical problems and things you wonder about, and the exhaustion cannot be discussed.
- They are not medical. I can't expect them to reassure me in any way about the way the thing went. As it happens, I do tell them about it anyway, but I take what they say with a pinch of salt. They're going to say: " Well, of course you did your best under the circumstances" etc, etc. I suppose it's good for me to hear that from them. Sometimes they ask for details and you say: " This is crazy, what's the point in me telling you, because this and this and this", when you know you haven't got a clue what it is. That is the case; otherwise I'd be talking to them a lot more of the time.
- I've got a very good, supportive family, but talking to them about medical issues, I don't feel that they've got particular insight into things. I think they're interested in what I do. There's not a question about that. I'm the one withholding rather than offering.

COLLEAGUES

The registrars access their colleagues at times. The discussion usually centres on clinical matters and seldom proceeds to more emotional issues. Although, it seems that non-verbal communication, like a pat on the shoulder, a look, or a sigh seem to provide some comfort in times of distress.

- When you review your management - those are often the times when you seek reassurance from your colleagues. You'll go to someone who you have some sort of relationship with, and say: "What would you have done in the circumstances? This is what I did." You're desperately seeking them to say: " Oh, I would have done the same". I don't think you can be blamed for that. That's what you want to hear from them and it's very helpful. You often walk away feeling like they've just said it because they know that's what you want to hear.
- I think by talking to each other, we're probably more factual than anything else. We don't actually voice our feelings about it, of anger or pity, or distress, or anything. Up to a point maybe yes, just a little bit.
- My initial response was really to communicate with my colleagues about it, to try to talk it out, to understand issues within myself, to come to terms with the reality that while I feel bad, perhaps there is the reality that there was not more differently that I could do. I hadn't taken it further than that.
- I remember the other registrar, I was working with, coming in and patting my shoulder and walking out again. He was sort of this manly kind of man.
- Then my colleague, I have become extremely good friends with, will hear about it as well. He's somebody that I can go to and say: "Look I did this. Do you think that was the wrong thing to do or was it a mistake?" We'll discuss it from a

medical point of view. So, I have another objective opinion about the way I've decided to do things on various patients, especially considering we both run the unit together. When I have things to discuss, I can go to him and say: "I gave this dose. Do you think it was the wrong or the right thing?"

CONSULTANTS

The registrars divided the consultants into two groups, those who are approachable and those who are not. The latter group seems to be much more prevalent.

- Some consultants are approachable and some aren't.
- There are only some consultants who do that (support a registrar,) and I think that's how they earn their respect, some of them. Some of the very experienced senior consultants are able to do that, but I can probably count on two fingers.
- I've got a fantastic consultant who I can talk to. I had to make a big decision about a patient who I sent home to die. She comes and then she supports you.
- Having had four deaths on duty, you may tell your colleague who comes on: "It's been a shitty night". That's the end. That's all what you say, really. You often don't have a consultant who's willing to come in and help during that. You've got certain consultants who are brilliant and who, out of their own bat, if you phone and say: "This patient has just died", will come in and help you with it.

The registrars pondered, though, to what extent the consultant's availability depends on a proactive stance of the registrars. They were generally uncertain about what kind of experiences would justify their request for some discussion regarding emotional issues.

- In general, I haven't identified a single consultant that I could relate to well at that point, that I could go and say: "I want to talk to you about this resus or something else". The problem hasn't seemed big enough to go there. In a sense that could be a gap in that maybe the problem shouldn't be so big, shouldn't need to be so big before I could come and talk to a consultant.

The registrars expect a consultant to play a supportive role in addition to his/her clinical and decision-making role.

- I think, ideally, the role of the consultant extends to a supportive role in addition to their decision-making role. In a sense, that they're the head of a team, team managing a patient and that should be inculcated into the wards itself. So, whenever there are situations that have gone well or gone badly, and I mean when a child dies it doesn't always mean that things went badly, but just where there's been difficulties or different opinions, the consultants should be able to provide support or keep a framework in which those things are discussed outside of a ward round medical situation. A lot of those things actually aren't resolved. People leave that case and go onto their next ward without having taken away or having learnt from it as much as they could have.

It is highly appreciated by the registrars when the consultant recognizes and acknowledges psychologically stressful events.

- I think if you went to any of them (consultants) and ask them for advice, they probably will do it. Most of them are very nice people all in all. But very few of them will come to you after an event like that and ask you: "How do you feel about it?" which has happened with Prof. X who came to me and asked me what happened. That never happened with anybody else.
- I remember a consultant coming in, in the middle of the night, simply because I phoned him to say I thought we'd reached the end of the line with this child, and I'd phone the parents, and they were coming in now, and that I would speak to the parents when they got here. You do that as a matter of courtesy and not because I want him to come in. He just pitched up here half an hour later and said: "I know it's gonna be hard on you, so I thought I'd be here to help you through it". He told me then the next morning to go home and rest for the day and come back the next day, which you never get told to do. You just have to get on with your next day's work. So there have been consultants who are different, but on the whole they are not there in the middle of the night, and often they don't say anything the next morning, except like: "What happened?" and "What did you do?" and that just sort of thing.

The consultant's help alleviates the registrar's feelings of guilt and failure.

- Initially I was blaming myself for the child who died, and in the end the head of the unit came to me. He'd heard about the child that died. He asked me to talk about it. We went through it and it turned out that there was nothing I could have done anyway, although the child died. But until that then I was feeling dreadful. I thought it was because of a failure, a technical failure on my part.

It was suggested that feelings should be discussed within a specifically designated space where both the registrar and the consultant could resolve their own issues, paying attention to each other's personality and working styles.

- The baby passed away. The registrar I was working with was distraught and crying. The parents were crying. My response to her was: "It happens quite frequently, babies having been born prematurely and dying". I don't know, sort of: "Get over it." I tried to rationalise it. Then my consultant, during my three month assessment period, said to me that she was impressed with my working ability, but this thing bothered her a bit because what she would have wanted me to be more supportive and be more like give her a hug, like hold her hands, it's alright to cry, I'm so sorry it happened. To be more emotional, more sensitive - that's somebody you are, that's not something you read in textbooks and then do.
- She (consultant) was concerned. That was just advice, it was friendly criticism. She did not mean it in the hard way, but I think what happened here was, she was reflecting her own approach. She's someone who's very emotional, and I frequently find her crying.

THE SUGGESTED SUPPORT

None of the registrars was against implementing some support structure, although some viewed it as a luxury rather than necessity. They felt that such support should be easily available, particularly for young doctors who are in the process of developing their attitudes and working styles. Not all of the registrars would use such support, though. Those, who would not, described themselves as used to coping on their own and not being able to open up easily.

- There'll always be deaths in hospital, so there is probably always a need, especially junior doctors, young doctors who are not used to doing it, to be counselled at times.
- I've never been involved in (counselling for doctors), or something which may be healthy, but I would perceive it as a luxury rather than necessity.
- I'm not receptive to counselling or anything like that. It's just that people have different ways of getting over things, thinking things through.

The registrars suggested several ways by which doctors could optimise their emotional well being while facing a dying child.

REGULAR DEBRIEFING SESSIONS

The sessions would serve as a forum to discuss both the clinical involvement with a child who died and the emotional content arising out of it. They would be run by a facilitator. Although it is time consuming, it may be quite effective in terms of normalizing feelings, getting rid of some emotional burden, and coming to terms with multiple deaths.

- There would be a facilitator. People would be given a chance to express their responses to the situation. I think what was quite effective, which we did once before in a case where a child died as a result of a mistake being made also in an ICU setting, was that there were sort of debriefing sessions thereafter, whereby the facilitator allowed people to speak about the sort of medical management, which was reasonably safe, even though that was where the mistake was made. But then we moved on to what people's feelings were, and what their responses were, and what they were gonna do with that, and how they felt. I think that was quite effective. It's quite time consuming. There's a whole team of people involved. But I think there are ways of doing it on a regular basis. It's difficult. You're in an ICU with 17 patients that are done and the turnover is high. There's quite a few patients who might die each week, but there should be a way of doing it. I think one could discuss the specifics as to the medical side and then go onto what people felt about the case and what their relationships were with the child and with the family.

“AD HOC” SUPPORT GROUPS.

One of the registrars suggested a designated place in the hospital for medical professionals who would have an opportunity to talk about their feelings, when they need it most.

- You deal with so many deaths. I don't know how feasible it is to deal with each person who's involved in the death individually. Ideally, everyone should have some degree of debriefing where they can just sit down and look at what has happened.
- It would be nice to have some sort of debriefing. It doesn't have to be every death, but just occasionally to have some sort of department where you can sit down with a group of people and they can talk about their feelings. Sometimes you have a bad night. I've been on call where I've lost four babies within three hours, and if you've resused each one, you sit down somewhere and you're absolutely finished. You can't give anymore, you just can't. It's very, very draining. It really is, but you know you're working in the state department. There's no rest in the state. There's no one to back you up. You've just got to pick yourself up the next day, get back in the trenches and fight the battle. Keeping kids alive is a battle.

INDIVIDUAL COUNSELLING SESSIONS

One registrar mentioned the possibility of having sessions with a therapist or a counsellor.

- I think also one could speak to therapists and counsellors. I'm not currently in therapy, but I think that's another possibility.
- It would be nice if there is some kind of counselling, if you are stressed out to go and get help.

DISCUSSION

The study shows that the doctors experienced the hospital environment as stressful. Death and dying is just one facet of multiple stressors that doctors have to deal with in their everyday work. Yet, it seems the hospital system offers the registrars very limited emotional support.

The registrars emphasized that the professional acculturation of doctors imposes the code of self-control and a coping attitude in every situation, irrespective of the physicians' internal feelings, anxieties, and fears. This attitude, perpetuated since the early years of medical school, does not acknowledge doctors' own emotions and may contribute to false perceptions that they do not experience a wide range of feelings as other professional groups might do. Such a stance, strongly reinforced by the medical professionals themselves at all levels of their professional advancement, might have led to the current situation where there is virtually no formal and very little informal support for doctors.

The registrars perceived consultants as one of the most important sources of emotional support. Yet, they reported that there are very few consultants who fulfil that role. There may be several explanations for such a situation. 1) Consultants themselves have received very little guidance about addressing the issues of death and dying and may feel uncomfortable with raising such a discussion themselves. 2) Their professional acculturation does not allow the space for an open acknowledgement of feelings. 3) As registrars noted, perhaps they had not been proactive enough in soliciting the support that they needed. 4) A proactive attitude can only be exercised in an atmosphere of well-developed mutual communication, thus the question arises: what are the communication styles among doctors? These hypotheses, however, require further research.

In the absence of support from the consultants the registrars turn to their colleagues, families, or no one. In a study of paediatricians, Khaneja and Milrod (32) report that family members and friends were the major sources of emotional support. Although the registrars in this study turn to their families and colleagues, who may be friends at the same time, the support which they receive is seldom perceived as satisfactory, except for support from the medical spouses. Support from colleagues seems to be more clinical than emotional. Similar factors that were mentioned with the consultants' support may play a role here. Support from non-medical spouses is helpful. Yet, most doctors felt ambivalent about using their families as a support base because of concern about putting an unnecessary burden on them.

Although all registrars expressed the need for more structured support within a hospital system, similar to Khaneja and Milrod's study, not everyone would use it. The reasons offered by the doctors are: 1) personality characteristics, with difficulties about opening up, 2) work load and time constraints, and 3) the perception that support is much more important at the beginning of registrarship, more clinical experience provides the doctors with better coping skills. I would also hypothesize that with doctors' deeply engrained professional coping styles, irrespective of the personal toll, some could perceive utilizing hospital support as a proof of their weakness.

The registrars presented some ideas around establishing a hospital support system.

1. **Regular debriefing sessions for the whole team dealing with a dying child.** It seems that this suggestion would be compatible with a paradigm of group therapy. Although, as noted by the registrars, such group sessions are time consuming, several therapeutic factors could turn out to be beneficial. Block (5), researcher of group therapy, lists the following factors that influence the individual: group cohesiveness, learning from interpersonal action, insight (self understanding), universality, instillation of hope, altruism, guidance, vicarious learning, catharsis, and self-disclosure. It is hypothesized that should the above sessions be run regularly with the same staff by a facilitator, with the passage of time the team would be able to build the capacity, skills and knowledge for independent support of one another. The facilitator then would be needed only in very difficult cases.
2. **"Ad hoc" support groups.** These groups would work in a paradigm of crisis intervention. The term 'crisis intervention' applies to people with stable personalities and a history of adequate coping resources who are facing major, but transitory difficulties (13). The group would centre on "emotion –focused" coping, in contrast to "problem-focused" coping, which usually takes place outside the group situation. The benefits of such intervention could be as follows: the expression of emotions, lowering of arousal and distress level, enhanced communication, increased group's understanding of their problems and their responses, bolstering the group members' self-esteem, and enhancement of further problem solving behaviour.

3. **Individual counselling/ therapy.** There is always a place for individual counselling or therapy, which could benefit the doctor in terms of further individual and professional growth. This option can be exercised at any point of the doctor's professional career, independent of the hospital support system.

CONCLUSION

The non-existent hospital support system is influenced among other factors by doctors' professional acculturation at all levels of their careers. Despite being aware of their feelings, doctors as a group tend to deny them. Emotional non-sharing deprives the doctors of an opportunity for further learning and growth. As Sahler et al. point out: "Striking a balance between the needs of the student as a person and the needs of the institution as a health care delivery system is key to accomplishing all of the medical service and all of the emotional work that must be done" (56). It requires, however, a major shift in thinking and perceptions that doctors hold about themselves. The suggested support groups could be the first step towards facilitating that change.

RECOMMENDATIONS

The researcher suggests the registrars, both junior and senior, attend a regular support group, which could be arranged by a facilitator once a month. It is hypothesized that more frequent support groups will not be attended because of the registrars' time constraints and workload. The group would aim at discussing all the psychological stressors that impact on the doctors' functioning, not death and dying alone. Combining the junior registrars with the senior ones would facilitate an exchange of experiences and mutual support. It could also provide some guidance and instil hope.

A concurrent monthly support group is suggested for the consultants who are perceived by the registrars as the most desirable source of support. Although the consultants are not the subject of this study and their opinions about the role of hospital support are unknown, it is thought that such a group could facilitate a dialogue between them and the registrars as well as addressing their own stressors.

CHAPTER 4: FINAL CONCLUSIONS

Despite the fact that results of this study are not necessarily generalizable to all clinical staff of the hospital, the findings bear consideration by hospital staff and training institutions. Many of the issues raised by the registrars are supported by literature and have implications for development of strategies aiming at improvement of quality of care of the dying child and his/her family, as well as optimising doctors' coping.

Dying and death of a child constitutes a very tragic and distressing event for the child himself/herself and everyone who is involved in his/her care: the family, friends, and the health professionals.

Death is an extremely evocative topic. It challenges everyone's attitudes and beliefs. It also awakens deep anxieties and one's sense of mortality.

It is not a pleasant or likeable subject in our contemporary times when youth and longevity are celebrated. The dying are sent to hospitals, morgues, and funeral parlours in a further attempt to deny death. Despite the fact that doctors are those few who face death on a regular basis, denial seems to permeate hospital institutions equally successfully. Death education in medical schools, although provided, does not meet its goals. The practice of medicine is geared towards technological progress and conquering illnesses at every possible biological level, from organs and tissues, to cells and DNA. So what happens to other aspects of the patient: psychological, cultural, spiritual?

One could argue that these other aspects do not primarily belong to the domain of medicine and should be left for other professionals to be dealt with. That would perpetuate the Cartesian split of body and mind, which in fact enabled us to see how much connection there is between these two in recent developments of psychoneuroimmunology.

It seems that the time has come to consider issues of death in a different light. The AIDS epidemic in South Africa has forced the medical fraternity to stop denying what is in the longer run undeniable. Death has to be spoken about and accepted as part of medical practice. Acknowledgement of this fact requires a shift in thinking among medical practitioners and openness about it. Physicians have to realize that, irrespective of how strongly they will defend themselves against death, it will always affect them in some way. This study clearly showed that death, although only one of the hospital stressors that the doctors are faced with, has more than a negligible effect on their professional and personal life. *

The relationship with dying patients, particularly with whom the registrars closely bonded, is a source of deeper emotional experience, which may be both very satisfying and rewarding or frustrating, sad and causing them to withdraw or detach. It is the quality of the doctor-patient-parent relationship, which provides the doctors' function with a deeper meaning and motivation to perform his/her duties. It would be highly regrettable and to the doctor's detriment if this function were delegated to other

professionals. In this light, it is of utmost importance to equip clinicians with knowledge and skills enabling them to establish good rapport, effective communication, and mutually satisfying relationships with the patients and their parents.

It is also important to look at their own emotional development and their own anxieties since these, when not addressed, may stand in the way of providing good terminal care.

This study shows that there is not a tradition of intercollegial support among doctors. Professional acculturation of doctors leads to suppression of many feelings, imposes very high standards of clinical performance with little tolerance for doctors' weaknesses, and pays very little attention to doctors' psychological well-being.

This study raises awareness not only of a dying child and his/her parents, but also of the medical practitioner who is in the middle of the situation, who is subjected to multiple pressures all around, and who is seldom asked about how s/he really is. International trends show that many doctors leave the profession. This research did not intend to answer why it happens. However, it showed what demands and expectations are imposed on medical professionals and what strengths one has to possess in order to cope in this occupation. The question remains: "For how long and what price do the doctors pay for such coping?" Hopefully, further research projects will be able to address this question, which could not be more relevant in the current South African context.

CHAPTER 5: LIMITATIONS AND STRENGTHS OF THE STUDY

LIMITATIONS

This study is limited by the following factors:

1. Methodological factors listed under “Researcher’s Bias” (the Methodology Chapter, p. 15)
 - The researcher’s medical training could have led to significant identification with the participants;
 - The researcher’s own limited teaching about death and dying during medical school;
 - The researcher’s work in paediatrics, encountering dying patients there and holding her views about it, could have caused stronger identification with certain aspects mentioned by the registrars at the expense of others;
 - The current involvement at RCCH and observing responses of the nursing staff towards dying children could have contributed to overemphasizing certain attitudes, which may not be so important in the doctors’ case;
 - The researcher’s psychiatric qualifications could have had an impact on the way data was collected and interpreted;
 - Conducting interviews in English, which is the researcher’s second language, could have led to the omission of some language nuances.
2. The small number of participants, who come from a senior group of registrars, from one tertiary hospital, in one city of South Africa, may not be representative of experiences of paediatric registrars in general. Thus, empirically this study is not generalizable. Theoretically it could be generalizable for the following reasons.
 - “The information derived from *any participant* is valid because that account is a product (albeit complex) of the social domain.” (27, p. 15);
 - It is possible that the most analyzed processes work in the same way across all health care professionals since they are universal, like grief responses, coping, bonding with the patient, cultural differences, professional growth;
 - The rigor of analysis built up plausible explanations, which could be easily tested out among other professionals dealing with dying children.
3. Gender of study participants: there were 7 male doctors and 1 female doctor. It is known that there are gender differences in approach towards issues of death and dying (Balswick and Peek, 1971 in 4, 19);
4. The senior registrars’ experience: junior registrars could have provided a different account. They could have been more distressed and less reflective.

STRENGTHS

The study has the following strengths:

- The subject of the study has not been addressed at RCCH before. It is also inadequately addressed in literature.
- The registrars were open to the research idea and provided an in-depth account of their experiences.
- The study has led to practical recommendations addressing the needs described in the narrative.

FINAL COMMENT

Prof. Oliver Wendell Holmes used to say to his students that, while one of the physician's functions is to assist at the coming-in, another is to assist at the going-out (38). I hope this study will contribute towards making these functions more balanced.

University of Cape Town

CHAPTER 6: SUMMARY OF RECOMMENDATIONS

All the recommendations resulting from this study could be included in following categories:

REGISTRARS

It is suggested that registrars:

1. Be more proactive in obtaining support from their consultants;
2. Look at their own attitudes towards death and dying;
3. Be supportive of each other;
4. Attend to symptoms of early burnout.

DEPARTMENT OF PAEDIATRICS

It is recommended that the Department of Paediatrics:

1. Acknowledge the stressful nature of registrarship and the impact of an increasing number of dying children, particularly on junior doctors;
2. Facilitate a dialogue between registrars and consultants concerning the psychological aspect of their work;
3. Establish a forum for the consultants where issues of such a nature could be discussed;
4. Review the clinical teaching around issues of death and dying, palliative care, and quality of life.

DEPARTMENT OF PSYCHIATRY

It is proposed that the Department of Psychiatry:

1. Review the current teaching regarding child psychological development, age appropriate communication with a child, the principles of care for bereaved parents, and introduce basic education about cultures relevant to medicine;
2. Provide assistance in organizing workshops aimed at increasing students' awareness of their own attitudes towards death and dying.
3. Contribute towards palliative care training.

HOSPITAL MANAGEMENT

This study showed that a dying child is just one of many stressors the doctors have to deal with in the hospital. It is suggested that hospital management:

1. See to the excessive work load enabling registrars 'to do the job properly';
2. Establish a formal support structure for the registrars;
3. Establish a full-time post for a hospital psychologist whose expertise could serve both the patients and their parents as well as the hospital staff;
4. Foster open communication around death and dying to prevent professional burnout.

SOCIAL WORK DEPARTMENT

This study indicated that many registrars value the social workers' practical input regarding counselling. The doctors also noted that most follow-ups of bereaved parents are seen by the social workers, but it seems that there was hardly any communication between the doctor and the social worker in this regard, and limited knowledge about the social workers' role. Thus, it is proposed that the Social Work Department:

1. Becomes actively involved in the practical training of students;
2. Acquaints the doctors with the social workers' role.

FURTHER RESEARCH

It is recommended that the following areas receive further attention:

1. Parental satisfaction with service provision at RCCH;
2. Factors influencing parental passivity;
3. Impact of the doctor's work on their personal life;
4. Some aspects of provision of care for patients and parents with HIV/AIDS.

REFERENCES

1. Abrams, M. Death and Meaning in a Storefront Church. *Public Health Nursing* 2000; Vol.17 No2: 132-142
2. Barbour, R. The Impact of Working with People with HIV/AIDS: a Review of the Literature. *Soc. Sci. Med.*1994; 39: 2: 221-232
3. Berman, S., Villarreal, S. Use of a Seminar as an Aid in Helping Interns Care for Dying Children and Their Families. *Clin Pediatr* 1983; 22:175-179
4. Behnke, M. Setzer, E., and Metha, P. Death Counseling and Psychosocial Support by Physicians Concerning Dying Children. *J Med Educ*1984; 59:906-908
5. Block, S. An Introduction to the Psychotherapies. 3rd Edition, Oxford Medical Publications.1996
6. Bluebond-Langner, M. The Private Worlds of Dying Children. Princeton, NJ: Princeton University Press 1978.
7. Bluebond-Langner, M. Meanings of death to children. In H. Feifel (Ed.), *New Meanings of Death* (pp.48-66). New York: McGraw-Hill. 1977.
8. Bowlby, J. Attachment and Loss: Volume III: Loss, Sadness and Depression. New York, Basic Books. 1980.
9. Brent, D.A. A Death in the Family: The Pediatrician's Role. *Pediatrics* 1983; 72: 645-651
10. Brewster, A.B. Chronically ill children's concepts of their illness. *Paediatrics* 1982; 69: 355-62
11. Buckman, R. Breaking bad news: why is it still so difficult. *BMJ* 1984; 288: 1597-9
12. Callahan, D. Death and the Research Imperative. *N Engl J Med* 2000; March 2, 654-656
13. Caplan, G. An Approach to Community Mental Health. Tavistock, London. 1961
14. Committee on Psychosocial Aspects of Child and Family Health. The Pediatrician and Childhood Bereavement. *Pediatrics* 2000; 105:2: 445-447
15. Day, R.A., How to Write and Publish a Scientific Paper. 3rd ed. Cambridge University Press. 1989
16. Denzin, N.K., Lincoln, Y.S., *Strategies of Qualitative Inquiry*. Sage Publications. 1998
17. Denzin, N.K., Lincoln, Y.S., *Collecting and Interpreting Qualitative Materials*. Sage Publications. 1998
18. Dey, J., *Qualitative Data Analysis. A User-Friendly Guide for Social Scientists*. Routledge. 1993
19. Dickinson, G.E., Pearson, A.A. Sex Differences of Physicians in Relating to Dying Patients. *JAMA* 1979; 34: 45-47
20. Emanuel, E.J., Emanuel, L.L. The promise of a good death. *Lancet* 1998; 351: (suppl II): 21-29
21. Fulton, G.B., Metress, E.K. *Perspective on Death and Dying*. Jones & Bartlet Publishers. 1995
22. Goldman, A. *Care of the Dying Child*. Oxford University Press. 1994.
23. Granger,C.E., George, C., Shelly, M.P. The management of bereavement on intensive care units. *Intensive Care Med* 1995; 21: 429-436
24. Gyulay, J.E. *The Dying Child*. McGraw-Hill Book Company, Blakiston Publication. 1978.
25. Hall, J.A., Dornan, M.C. What patients like about their medical care and how often they are asked: A meta-analysis of the satisfaction literature. *Soc Sci Med* 1988; 27: 935
26. Harper, M.B., Wisian, N.B. Care of Bereaved Parents. A Study of Patient Satisfaction. *J Reproduc Med* 1994; 39:80-86

27. Hollway, W. Subjectivity and method in psychology: Gender, meaning, and science. London. Sage Publications. 1989.
28. Howells, K., Gould, M., Fields, D. Fear of death and dying in medical students: effects of clinical experience. *Med Ed* 1986; 20: 502-506
29. Hull, F.M. Death, dying and the medical student. *Med Ed* 1991; 25: 491-496
30. Kachoris, P.J. Psychodynamic Considerations in the Neonatal ICU. *Crit Care Med* 1977; 5:62-65
31. Kaplan, H.I., Sadock, B.J., Grebb, J.A. Synopsis of Psychiatry. 7th ed. Williams & Wilkins. 1994
32. Khaneja, S., Milrod, B. Educational Needs Among Pediatricians Regarding Caring for Terminally Ill Children. *Arch Pediatr Adolesc Med* 1998; 152:909-914
33. Knapp, R.J., Peppers, L.G. Doctor-Patient Relationship in Fetal/ Infant Death Encounters. *J Med Educ.* 1979; 54:775
34. Kubler-Ross, E. On Death and Dying. New York. Macmillian Co. 1969
35. Kubler-Ross, E. On Children and Death. Macmillan. New York. 1983
36. Kubler-Ross, E. Death. The Final Stage of Growth. Prince Hall Inc. Englewood Cliffs, New Jersey. 1975
37. Lansdown, R., Benjamin, G. The development of the concept of death in children aged 5-9 years. *Child: Care, Health and Development* 1985; 11: 13-20
38. Linn, B.S., Moravec, J., and Zeppa, R. The Impact of Clinical Experience on Attitudes of Junior Medical Students about Death and Dying. *J Med Educ* 1982; 57:684-691
39. Maguire, P. Barriers to psychological care of the dying. *BMJ* 1985; 291: 1711-13
40. Marshall, C., Rossman, G. Designing Qualitative Research. 2nd ed. Sage Publications. Thousands Oaks. 1995
41. Mason, J., Qualitative Researching. Sage Publications. 1996
42. McFarland, K.F., Rollins, E.C., Gonzales, M.F., Rhoades, D.R. Dealing with death and dying. *Med Ed* 1994; 28: 136-138
43. McHaffie, H.E., Laing, I.A., Lloyd, D.J. Follow-up care of bereaved parents after treatment withdrawal from newborns. *Arch Dis Child Fetal Neonatal Ed* 2001; 84: F125-F128
44. Mermann, A.C., Gunn, D.B., and Dickinson, G.E. Learning to Care for the Dying: A Survey of Medical Schools and a Model Course. *Acad. Medicine* 1991; 66:35-38
45. Meyers, A., Weitzman, M. Pediatric HIV Disease. The Newest Chronic Illness of Childhood. *Pediatric Clinics of NA* 1991; 38:169-194
46. Miles, M.B., Huberman, A.M. An Expanded Sourcebook: Qualitative Data Analysis. 2nd ed. Sage Publications. Thousands Oaks. 1994.
47. Mndende, N. African Traditional Attitudes to Death and Dying. *CME* 1997; 15:793-798
48. Nash, E., Stoch, B., Harper, G. Human Behaviour. Juta & Co, Ltd. 1990
49. Oliver, R.C., Sturtevant J.P., Scheetz, J.P, Fallat, M.E. Beneficial Effects of a Hospital Intervention Program after Traumatic Childhood Death. *Journal of Trauma Inf Crit Care* 2001; 50: 4: 440-448
50. Perez-Carceles, M.D., Osuna, E., Luna, A. Medical Personnel and Death. *Med Law* 1999; 18: 497-504
51. Raphael, B. The Anatomy of Bereavement. Basic Books. New York. 1982
52. Rowe, J., Clyman, R., Green, C. et al. Follow-up of families who experience a perinatal death. *Pediatrics* 1978; 62:166

53. Sack, W.H., Fritz, G., Krener, P.G., and Sprunger, L. Death and the Pediatric House Officer Revisited. *Pediatrics* 1984; 73:676-681
54. Sahler, O.J.Z. *The Child and Death*. The C.V. Mosby Company, St. Louis. 1978
55. Sahler, O.J.Z., McAnarney, E.R., and Friedman, S.B. Factors Influencing Pediatric Interns' Relationship with Dying Children and Their Parents. *Pediatrics* 1981; 67:207-215
56. Sahler, O.J.Z., Frager, G.R.N., Levetown, M., Cohn, F.G., Lipson, M.A. Medical Education About End-of-Life Care in the Pediatric Setting: Principles, Challenges, and Opportunities. *Pediatrics* 2000; 105: 3: 575-584
57. Saunderson, E.M., Ridsdale, L. General practitioners' beliefs and attitudes about how to respond to death and bereavement: qualitative study. *BMJ* 1999; 319: 293-296
58. Schowalter, J.E. Death and the Pediatric House Officer. *J Pediatr.* 1970 76:706-710
59. Schowalter, J.E., Ferholt, J.B., and Mann, N.M. The Adolescent Patient's Decision to Die. *Pediatrics* 1973; 51:97-103
60. Seale, C. Changing patterns of death and dying. *Soc Sci Med* 2000; 51: 917-930
61. Simeonsson, R., Buckley, L., Monson, L. Conceptions of illness causality in hospitalized children. *J Ped Psych* 1979; 4: 77-84
62. Slaby, A.E., Glicksman, A.S. *Adapting to Life-Threatening Illness*. Praeger. 1985.
63. Spinetta, J., Maloney, L. Death anxiety in the outpatient leukemic child. *Pediatrics* 1975; 56:1034-1037
64. Spiro, H.M., McCrea Curnen, M.G., and Wandel, L.P. *Facing Death. Where Culture, Religion, and Medicine Meet*. Yale University Press. 1996
65. Swartz, L. *Culture and mental health: A southern African view*. Oxford University Press. Cape Town. 1998.
66. Tanaka, T., Gotay, C. Physicians' and Medical Students Perspectives on Patients' Quality of Life. *Acad Med* 1998; 73: 9:1003-1005
67. Todres, D., Howell, M. C., and Shannon, D.C. Physicians' Reactions to Training in a Pediatric Intensive Care Unit. *Pediatrics* 1974; 53:375-383
68. Waechter, E. Children's awareness of fatal illness. *Am J Nursing* 1984; 71: 1168-1172
69. Wiener, J.M. Attitudes of pediatricians toward the care of fatally ill children. *J Pediatr.* 1970; 76:700-705
70. Wolfe, J., Grier, H.E., Klar, N., Levin, S.B., Ellenbogen, J.M., Salem-Schatz, S., Emanuel, E.J., Weeks, J.C. Symptoms and Suffering at the End of Life in Children with Cancer. *N Engl J Med* 2000; Feb3, 326-333
71. Zeanah, C.H., Lieberman, A.F., Disorders of Attachment in Infancy. *Child Adolesc Psych Clin N Amer* 1995; July 4:3:571-587
72. Power, D. Statement on Care for HIV-Infected Children in South Africa. *MCH News* 2001; 17: 3

DECLARATION

I, Marta Lik, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise), and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the University of Cape Town to reproduce for the purpose of research either the whole or any portion of the contents in any matter whatsoever.

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