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Twenty Years On............
Has Policy Become Practice in Your Paediatric Wards?

Report of a Seminar held at the King's Fund Centre
on Thursday 29 January, 1981

Report by Diane Sayle

April 1981

King's Fund Centre
126 Albert Street
London NW1 7NF

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King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

TWENTY YEARS ON - HAS POLICY BECOME PRACTICE IN YOUR PAEDIATRIC WARDS?

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'Children in Hospital' - A report on the extent to which hospitals have implemented DHSS recommendations since the Platt Report

Information sent to participants prior to this seminar included:

- Highlights of the report 'Children in Hospital' as it appeared in 'Which?' in June 1980.
- Consumers' Association Action Guide for Parents 'Children in Hospital'.

The Consumers' Association Report is available from:

The Consumers' Association
14 Buckingham Street
LONDON WC2

Price: £15.00. The DHSS have arranged for copies to be available in AHA and RHA Libraries.

During the day there was an opportunity to see the film 'They're Children - They're Different'. The film is aimed at promoting an awareness of the special needs of children's hospitals. The 34 minute film has been made for the Department of Health and Social Security by the Central Office of Information. The film can be borrowed, free of charge from:

The Central Film Library
Government Building
Bromyard Avenue
LONDON W3 7JB

and is available on 16 mm or video cassette. Both presentations are also available for purchase.

INTRODUCTION

On 29 January 1981, a conference was held at the King's Fund Centre entitled, 'Twenty Years on - Has policy become practice in your paediatric wards?' The aim of the conference was 'To develop the concept of change and in particular how staff with responsibility for children in a general hospital face the demands made of them by colleagues, children and relatives.' Those present were welcomed to the Centre by Assistant Director, Miss Hazel Allen, and she then introduced the Chairman, Professor Thomas Oppé, Director of the Department of Paediatrics, St Mary's Hospital Medical School, London W2.

Professor Oppé said the main reason for the conference was that, in parts of the country the practice of caring for children was not good. This had been pointed out by a valid, reliable piece of research by the Consumers' Association which said that those policies set out in the Platt Committee report and reaffirmed both in the circular for hospital facilities for children and by the Court Committee were not, in many places, being satisfactorily carried out. It was also fairly obvious that it was not only lack of money and lack of resources preventing implementation of the recommendations. By far the biggest two problems were:

1. attitudes - understanding of the basic needs of young children.
2. the real practical difficulties people have working with children in a general hospital.

People must be convinced by the presentation of hard data and by informing them that a great deal of harm would be done if the all round needs of children were not met while they were sick and in a strange environment.

Professor Oppé said he was delighted the conference was based on the Consumers' Association Report because the study had been based on very thorough research.

Dr Peter Maguire, Senior Lecturer, Manchester University.
'The psycho-social aspects of caring for the child and his family'

Professor Oppé then introduced the first speaker, Dr Peter Maguire, who was well known for the Maguire Report - a very critical look at medical education at St Mary's Hospital.

Dr Maguire began by reading part of the summary of the Consumers' Association Report. This was addressed to parents and concerned the attitudes of those working in the hospital.

> "However well trained and kind, nurses and doctors will still be strangers to your child. They cannot give the support and comfort that you are able to give. Hospitals should allow you to visit at any reasonable time. Aim to be with your child as long as he and you want."

Dr Maguire suggested that although the state of affairs regarding flexibility of visiting might be patchy in this country, perhaps in some ways there was a danger of the pendulum swinging too far and that, in his judgement, was as likely to have adverse consequences on the child and his family as the original policy of not allowing the family near the child.

He, therefore, wanted to argue for flexibility in terms of policy, and above all for being aware of what individual families needed, rather than having blanket policies. He said he wanted to justify this by referring to some work that had been carried out with a particular group of the population. But first he spoke on a historical note. The whole drive towards parents being with children in hospital came from the rather horrific claims in the early 1950s of the effects of maternal deprivation, the notion that a child being separated from a mother, even for a short time, could result in behavioural difficulties and be the precursor of later personal problems. Bowlby has said, in a recent review, that he is confident his work had a major influence in changing attitudes towards children in hospital.

Modern practice in theory is

> 'to encourage parents to visit as often as they wish, and to assume that by doing so and by enlisting the mother's help with practical care, the family is being helped to adjust to this trying time.'

Dr Maguire said they had looked at this as a by-product of some other work. The example used was an extreme one and he felt it highlighted the complexities involved in how parents and children should be treated when the child was suffering from serious illness. He was talking about children with a serious illness, particularly an illness which could threaten life and he was using this as a model to make certain arguments. The population looked at, consisted of sixty families who had a child diagnosed as having acute leukaemia. They were all being treated in the Manchester area and the investigation was concerned with finding out, over a period of eighteen months, what problems the family as a unit experienced.

Dr Maguire then used slides to illustrate further points. The first was depression. The survey was concerned with extreme cases, mothers or children who had not coped, and in psychiatry these mothers were defined as having developed abnormal mood states or morbid depression. This meant a consistent change in mood which the mother recognised as quite uniquely different from anything she had experienced before. She would be feeling extremely low spirited, weeping for no reason, feeling very gloomy and pessimistic and might even begin to question her whole future. This state had to last for at least one month before it was even considered to be a morbid reaction, but also it had to be accompanied by other symtoms - i.e. sleep disturbance, (early morning waking being the characteristic of a depressed person) mood feeling worse in the morning, accompanied by suicidal ideas. It was found that no less than one in five of the mothers looked at had developed the above sort of depression within twelve to eighteen months of their child being diagnosed as having acute leukaemia. Some of these women had to be admitted because they could not cope any longer, but far more of them struggled on, not giving a clue to anyone either in the hospital unit or community. So there was an enormous discrepancy between the perceptions of the carers as to how the mothers were coping and the reality of how they had responded to the strain of the disease in their child and the way their child was being cared for. The stress of serious illness had, for some mothers, very serious repercussions in terms of their mental health. Clearly, a lot more mothers were under strain which could drag them down although not to the 'extreme'.

The investigation was also interested in another kind of abnormal reaction - morbid anxiety. A sufferer from this was continually tense, unable to stop worrying, unable to get to sleep, jumped at the slightest noise, and was very wound up - it was a very unpleasant feeling. Twenty-four per cent of mothers with leukaemic children had this problem compared with four to five per cent of mothers of children with benign disease such as hernia.

From these findings, Dr Maguire emphasised that looking after children with serious disease put very considerable strain on the parents and some mothers just could not stand up to the strain. He felt there were several reasons for this situation and some had direct bearing on how the <u>carers related to the parents</u>. Follow-up studies had been done, interviewing the carers and the parents to find out what understanding they had as to why the stressful situation arose. Clearly before the carers became involved there was the stress of the disease itself. Many childhood diseases carried with them a great deal of uncertainly as to whether the child would recover.

> How did the parents manage that uncertainty and how did the carers help the parents to cope especially in the face to face situation in hospital? Could the carers hope to reduce the uncertainty or was it inevitable? The child might die from the disease over the next few years and the carers could not say with certainty that the child would not die. Had the carers a way or language for managing that kind of uncertainty, to help parents adapt better to the predicament?

It was found that one of the things which helped the parents and was linked to a better outcome was when staff, especially nurses, were prepared to give the parents 'markers', set goals eg. to say that if the child was in remission by a certain date that was good. This gave the parents a framework and it did not matter if the news was not hopeful, the parents would accept the goal because it was within the framework. What parents could not accept was not being told anything.

> So, what was the role of the carers in defining for each parent what markers they needed?

If markers were needed from the doctors rather than the nurses, making sure these were given in some meaningful form i.e. in words the parents could understand.

There were, of course, many other reasons relating to the family illustrating why some of the mothers could not cope. These were really related to certain central dilemmas that the mothers faced - so obvious when they talked about them.

> How much time should the mother spend with her sick child and how much with her healthy children?

The mother felt pressure to be with her sick child; she might have been told she should have been in hospital all the time with the child.

> How much time should she spend with her husband versus visiting the hospital all the time, and what consequences might that have? Should she give up her job? Were the child's needs so paramount that she should give up everything important to her and devote her time to the child?

Policies that insisted it was good for the mother to be with the child, carried with them a strong pressure on the mother to feel that she ought to relinquish all her other interests. In the act of relinquishing she was giving up vital areas of support - friends, contacts, workmates, that would ordinarily have kept her going when she was under stress.

It could therefore be seen, that the mother was becoming 'trapped' by the carers who, with the best of intentions focussed on the child and his needs. The mother, of course, felt when the child had a serious illness that she owed it to him to be there and, that it was wrong for her to have needs of her own. She felt it was very wrong of her not to want to go to the hospital when the child was so ill. Thus Dr Maguire said, there were fundamental dilemmas that mothers faced when their children were seriously ill, and these had not been analysed sufficiently - the carers just said glibly that of course mothers should be with their children most of the time.

Also, if the mother spent most of her time in the hospital she not only became detached from her family, but had to face the reality of what was happening to other sick children.

> How many deaths could she take on the ward, how could she then believe her child's outlook was better as the physician insisted? Also did anyone realise that she might need time away from the ward?

She might actually have to be persuaded to leave the ward for her own sake.

Dr Maguire spoke of a mother who had been admitted after an attempted suicide because she could not cope with her child's illness. She had told them of the effects of witnessing treatment.

> "It (his mouth) was terrible..... all the inside of his mouth, his tongue, down his throat, his gums were just masses of ulcers, he could not eat, his lips used to look like they had been burned."

This emphasised one of the consequences of being in hospital all the time, that the mother used to witness the real effects of the treatment. For example seeing the child with tubes in his body became indelibly imprinted on parents' minds. This might adversely affect any future contact they might have with the Health Service.

Dr Maguire continued by saying a lot of information had been collected related to the perceptions of parents and hospital admissions. Allowances had to be made, that the mothers interviewed were often under great strain. Even so, the mothers felt it was all too common for nursing staff to make them feel they must be in the hospital all the time and that the mothers should take over a lot of practical caring functions. This resulted in the child getting not just as much attention as he had had at home but four times as much.

> How realistic was this? What kind of expectations did this create in the child in terms of future demands the child made on the parents? How was this handled by the carers?

Long lasting repercussions were inevitable. In such a situation the mother felt she had to be with her child in the hospital although she wanted to leave, having concern for the rest of the family. Such a dilemma was increased by the caring profession indicating that her job was to be with the child. Increasingly, the mother became alienated from other people, from her husband and other children. Therefore this was another aspect to the theory that mothers should be with their children in hospital.

Dr Maguire said certain predictive factors had been found that allowed them to identify mothers who would have a particularly difficult, emotional time.

1. These were mothers who felt that during the hospital admission they had to bear the brunt and it was not shared with other relatives especially the husband. This could be noticed easily - mother doing all the visiting.

2. The course of treatment was stormy - with complications and unexpected relapses.

3. If the staff were perceived as not caring
   and of being too busy.

Dr Maguire stressed that he felt if the policy was pushed in an inflexible way more problems might be created than were resolved, for the families, especially the mothers.

But what of the children after discharge from hospital? The investigators were amazed at the number of children who subsequently had problems in their behaviour. About two in every five children developed a problem in their behaviour that represented a significant departure from their previous behaviour and in some cases severe problems. In line with Bowlby's original work a particular kind of dependency syndrome was found, which was said to be one of the consequences of childhood separation, where the child refused to be left alone in the first few days after discharge from hospital and constantly followed his mother around. Some of the childrem were 13, 14 and 15 years old and it was found that in some families the dependency syndrome had come to dominate family life e.g. some children would not sleep alone and slept with their parents. The mother gave in because she could not cope with the tantrums and was often frightened that something terrible night happen to the child if she did not keep constant watch on him. Thus such dependency problems might develop and persist unless outside help is given. Recent work has shown other common problems were refusing to go to school and eneuresis.

The reasons for dependency problems were interesting. One of the obvious ones was of parents finding it very difficult to treat a sick child as 'normal'. If the illness was a chronic, life threatening one this situation was intensified. Over half the parents commented that they had changed their behaviour towards the sick child in a marked way. In what kinds of way had they changed? The most common change was to make a fuss of the child, to be indulgent. Often the child was showered with presents usually in an effort to make up to the child for having 'failed' him. Failure was often the feeling of the mothers as part of her role was to see the child in good health through to adult life. Other changes in behaviour concerned protection - preventing him getting knocks and infections, and not disciplining the child because he might be dead in a few months. The percentage of changes in behaviour were:

Discipline	36%
Self Care	16%
Protection	40%
Indulgences	48%

(Maguire, Duberley and Morris-Jones 1977)

The patterns of 'over attention' continued for months after the child was discharged. Dr Maguire said they felt sure the roots of the behaviour problems in the children were not just due to the child's own reaction to illness uncertainty but also to these changes in people around him. It was thought the seeds of this began in at least some children with the abnormal amount of attention they got when in hospital.

Dr Maguire cautioned that although he was not arguing against children in hospital getting attention, there was a danger of going too far in our eagerness to improve matters and, in doing so, introducing a whole other set of problems which would take us back to square one. Once such patterns were established it was very difficult to change them.

Thus, there were problems because of strain for the mother, some of which linked back to how the carers responded and there were problems for the children. One of the key factors revealed in adolescent children was the relationship between behaviour problems and their lack of understanding about the disease. Four fifths of them had been given a cover story by the parents such as telling them, they had a kind of anaemia or 'blood disorder'. There was a very strong link between the children having difficulties and being 'kidded'. What was the role of the carers in trying to ensure that the child, if able, was given a sensible, reasonable understanding of the disease? What were the implications of this? How should this be done - for example, should it be verbal and on an individual basis?

Finally, Dr Maguire spoke of father and the siblings. A much higher incidence of problems in brothers and sisters was found than had been expected - one third of them had problems. These were less severe than those of the sick children but they were certainly present. The school teachers picked them up and some children had considerable difficulties. This linked back to two main sources.

1. Resentment of all the time parents, particularly the mother, spent with the sick child. The sibling felt guilty about his resentful feelings.

2. The siblings felt they had been kept apart, they had not been involved as sensible members of the family in the treatment and management of the sick child - this raised the issues of siblings visiting in hospital and how much they should be told about the illness, and possibly that the sick child might die. With so little information the siblings were baffled by the dramatic changes in their parents' behaviour. The siblings became very puzzled about the situation and, of course, tended to feel there must be something unlikeable of wrong with them, and so, they began to develop behavioural problems.

Dr Maguire said that some families they had been able to help most were those in this predicament, where it was easy to bring the problem out into the open and help communication.

<u>Dr Maguire asked what could be done about such problems.</u> One factor which had struck the investigators most in talking to the families and in subsequent studies of other children was <u>how little the families as a unit felt able to share with the carers what was going on</u>. Less than one in six of the families had communicated problems to anyone in a position to help in hospital or the community. In a recent study of General Practice these families were followed up and the general practitioners were asked about the situation. Their answers were that of course the situation was stressful. The parents would be upset and as GPs they could not alleviate this, also the mother owed it to the child to keep going and had no right to break down. Dr Maguire posed the question of 'how could the mother off load her anxieties?' Her husband had enough of the situation - he was living with it. If she had given up her job and supports she had no one. Dr Maguire said he was amazed that more mothers did not break down - the resilience of parents and children was remarkable in the

face of serious illness. We could not assume that families would tell the carers if they were having problems - we should monitor and establish their needs for visiting, for information and also try to discover any problems so that appropriate help might be given.

Dr Maguire then suggested the simple manoeuvre of listening. One of the things parents said repeatedly (and Dr Maguire felt this was a reflection of how people in hospital organised their lives) was how busy the carers appeared. It was difficult to broach worries under these circumstances. So how did we create time and space for people?

In a recent project where nurses were being trained, the nurses had actually been told off by ward sisters for wasting time talking to patients. Dr Maguire suggested there were some powerful factors in the way we worked, not just attitudes, that might make communication difficult.

> Were we really willing to create time and space for these families so we could identify their needs and find whether the pattern of visiting and being with the child was appropriate?

If we could find time to listen we might find that the families would spread out a series of very clear cues or signals that they were under pressure. Words like

> ".....unable to sleep for nights.....been worried out of my mind"

Would the carers take such a statement and explore it or retreat to the traditional nursing and medical practice of saying "Don't worry, everyone feels like that, you'll be better in a few days when your child gets better." Dr Maguire based these responses on several hundred training sessions he had carried out with nurses. He said responding like this was not from lack of concern or commitment. Perhaps it was a lack of knowing how; a lack of knowing how to create the space and time. Dr Maguire suggested the answer might be partly in pamphlets and booklets.

However, Dr Maguire felt there was really no substitute for appreciating the importance of early contact with the family when each family's heads could be identified and a pattern of visiting, contact and involvement that worked best for them, established. By doing this and by avoiding rigid policies a massive contribution could be made in reducing the kind of problems still being seen all too frequently.

Dr Maguire recommended for reading:-

JONES, Pat Morris- Topics in paediatrics: Haematology and Oncology. Tunbridge Wells, Pitman Medical. Vol. 1, 1979. £9.50.

Miss J Mander, Divisional Nursing Officer, Booth Hall (Children's) Hospital, Manchester.

Implementing change in the form of the Nursing Process - the considerations and the consequences

Before commencing her paper, Miss Mander spoke of two recent incidents. The first was in her own hospital one evening when a woman brought in her two year old son. The woman's husband was overseas; she also had a seven year old, and was breast feeding her third youngest child. The mother wished her au pair to stay in hospital with the two year old, but this was only allowed after telephone calls to Miss Mander and the Consultant because a Ward Sister had said "Mothers lived in and not mother figures."

Another incident had occurred that week with a staff nurse coming for interview. She was asked what she would do if the mother of a four year old with acute appendicitis wished to stay the night with him. She said if she was in charge, she would let the mother stay, but sister would not like it.

Miss Mander then spoke of the Nursing Process, and said her hospital had been working towards implementation of the Process for over two years. The Process was a method of assessing, planning, delivering and evaluating individual patient care. Although documentation was involved, the Nursing Process was not about documentation - it was a way of thinking. As nurses, it was vital to consider its effectiveness. Florence Nightingale said,

> "Let no woman suppose that obedience to the doctor
> is not absolutely essential"

but she also said,

> "Do not let the physician make himself head nurse."

Miss Mander suggested there were many incidences today where obedience to the doctor was absolutely essential but there were also incidences where a nurse should rightly query instructions. In the question of nursing care Miss Mander felt that for too long this had been effectively controlled by non nurses, not only doctors. With the Process nurses now had a tool enabling them to make logical decisions about care given, why these decisions had been made and how effective they had been. Nurses had not yet been successful in showing other professions how the Process was used, and indeed there were difficulties in showing some nurses but she felt such a radical change would take a very long time to filter through the hospital population.

Miss Mander felt it was easier to implement the Process in a children's ward or hospital than in a general hospital. The child could not be dealt with in isolation, without his family. Because of this, paediatric nurses were generally more attuned to recognising the individual needs of the children. Many of the staff at Booth Hall Children's Hospital were enthusiastic about the Process, and the initial momentum came from a nursing officer and a ward sister. However, there were still a lot of staff who needed to be convinced. Towards the end of the 1970s nurses were talking about 'The Process' and learners were being taught the principles of delivering patient care, but in the service area opportunities to fully implement the methods taught, were very restricted.

The first moves to fully implement the Process at Booth Hall came from a sister on a medical ward and a nursing officer on a Burns and Plastic Unit. They developed the existing brief care plans and then their histories. A nursing history was a record of a child's development, of any previous events which might affect his stay in hospital, his family, habits, and, if possible, his expectation of his stay. The idea was to standardise nursing histories throughout the hospital as far as possible but this had not worked. Today, two of the units out of five were fully using the Nursing Process, a total of eight wards. The Medical Unit, with five wards, had four history categories, age related:-

Under one year,
one to five,
six to eleven,
and twelve to sixteen

The Burns and Plastic Surgery Unit had the histories divided in the same age groups but each of the three wards in that Unit - Acute Burns, Cold Plastic Surgery and Orthodontics - had their own histories. The Surgical ward, when their plans were finalised, would probably have the four histories like the medical wards.

Miss Mander spoke of the question of cost. In August, 1978, stencilling of the paperwork was begun because there were so many changes being made. Stencils were cut for twenty two months and a quote from a commercial printer was obtained. For one unit for one year he quoted £1,200. At the same time the printing department in the district purchased a high quality copier and when the Medical Unit's work was printed using this machine 30,000 sheets of paper for a year for five wards worked out at approximately £54.00. It had been estimated that for the whole hospital the cost would be £350.00 a year and the hospital was spending £850.00 a year on Kardex stationery in 1979/80.

On the wards where the process had been implemented, the Kardex had been abandoned. With problem-orientated care plans there was an accurate record of the child's day and reports such as 'Good night' 'Slept well' 'Satisfactory day' 'No change' were no longer seen.

On some wards, as well as individual care plans, there were standard individual care plans which were designed for use on wards such as Plastic Surgery, to give learners a basic idea of routine care. They were not being used as much as had been expected. As said earlier, learners had been taught for some time in the School of Nursing to think in the Nursing Process way but were having difficulty in practising it. On wards where the Process was being implemented there were learners undergoing five different trainings:

> Combined SRN/RSCN course;
> SRNs taking post registration sick childrens' training;
> SRN students and SEN pupils on their paediatric allocation
> and undergraduate nurses from the University of Manchester.

They all appeared to enjoy being involved in planning care. The pupil nurses, who were only on the wards for eight weeks at the most, found difficulties but with encouragement and support seemed to cope. Miss Mander said she interviewed each intake of learners for the combined course, approximately six or seven months after beginning their training. At that time they had each had one paediatric and adult allocation and had been taught the principles of assessment, planning, delivering and evaluation of care. It was remarkable hearing them talk about wards where they were told what to do and wards where they were allocated their patients and they decided, with guidance, what the patients required. Miss Mander had recently read through care plans and histories on the medical ward where the work was first started and in one instance, the nurse responsible, who had only started training in April, 1980, had really got her plan of care worked out and each nursing action was soundly based. The speaker compared this with medical notes, where often a whole list of tests were written down and ticked off, 'done'. Miss Mander suggested that often this was to make sure nothing was missed and without consideration of whether each child needed all the tests.

Miss Mander was certain that no Divisional Nursing Officer could implement the Nursing Process in a hospital. She felt her main contribution had been support. She believed in the Process and felt it helped nurses to improve their care and to be more concerned with why they were taking certain actions. The only people who could carry it out were the ward staff and their nursing officers. They had to want to change and, if they did not see improvement, they would not change from their present practices. Seeing other wards changing, learning by example, and learners moving from ward to ward were the ways to spread the Process to all the wards.

People made the excuse of staff shortages but the wards where the Process had been implemented at Booth Hall were not generously staffed. There had been resistance from nursing and medical staff. Where a Kardex could be flipped through, a care plan had to be read so the reader knew what was happening with all sorts of problems.

The format of the nursing histories was still being changed. For example, at present only the 12 plus children were asked about smoking habits but this was to be added to the 6 - 11 year olds' group histories.

Miss Mander concluded that implementation of the Nursing Process could not be hurried. In Booth Hall paperwork was started in August, 1978, and it had been expected to take eighteen months to implement throughout the whole hospital. Two and a half years since the initial introduction, half the hospital were using the Nursing Process.

Dr Averil Earnshaw, Locum Consultant Child Psychiatrist, Burnt Oak
Child Guidance Clinic.
How are demands made by children?

Dr Earnshaw began by saying she had felt quite daunted when first given her topic because there were so many ways in which children made demands and so many different demands, and then demands changed year by year as children grew up. The main difference was that before a child could talk he made his demands physically and later they were made more in language.

At present, Dr Earnshaw was not working in hospital so she had asked colleagues and friends who were in hospital as children, to relate their experiences. She was struck by how alive and interested these people became when asked this question. Several said they clearly remembered some incidents but could not recall anything else about the experience. One remembered waiting with her face at the window to be fetched home; another the vomit dishes which were much too small; and another remembered being good and quiet so she could go home. These memories of today's adults might well match the experiences of today's children in hospital when there was no family with them.

The sequences of observable patterns of behaviour of children alone in hospital was protest, despair and then detachment. Dr Earnshaw said that in her experience of psychotherapy with children this sequence of feelings went on in mental life sometimes with little or no observable behaviour. She then asked a further question - 'What was it that children were demanding?' and she thought one of the demands was for continuity.
Dr Bowlby said that when we were little, one of our crucial needs was for someone who remembered what we did yesterday, perhaps, before we could remember ourselves - someone who kept us linked to ourselves in lifetime and who knew who we were. Being in hospital was inevitably a break in the continuity of anyone's lifetime. The person could feel very lost when it happened, and he tried to maintain his own continuity as best he could.

Dr Earnshaw said that everyone in childhood had at least two versions of their parents in their minds - the bad cruel ones, and the good ones. Breaks in continuity in an individual's lifetime, such as being in hospital, might dangerously increase these split views, so the speaker felt that a second, usually unspoken, demand of children faced with a break in continuity was for help in understanding their intense feelings.

One of the strains that workers in children's hospitals had to bear was this split view of grown ups; at one time a child would want his mother or father and not the nurse, and on another occasion vice versa.

It was not known why people became ill when they did, and while the practicalities of a hospital stay could be explained to a child, why it was happening could not be explained. Dr. Earnshaw felt it was in this area of the mind of perplexity and confusion that fears and misconceptions arose about what was going on and these might proliferate.

The event outside the person's control and which came without his asking for it, could be an overwhelming threat to his awareness of himself as an ongoing, continuing person. To reassure ourselves as to who we were we needed familiars (people and things to link us to our people) with us, to minimise the terrors of feeling lost in time and space.

Usually, as we grew up, we developed a store of memories of experiences negotiated with the help of kindly, friendly, thoughtful other people, so these experiences became points of growth - achievements.

Dr. Earnshaw went on to talk of her own research interest - anniversaries of life events. She believed we never had sole anniversaries. Our important people were always present in our inner world of memories and fantasies as residues of our early days. When parents took a child to hospital they were anxious about the real danger to the child, about their own intense feelings which sometimes shocked them, such as, 'What a relief to have some peace! ' There was the anxiety of managing ordinary chores plus the added burden of visiting and somehow the child sensed these anxieties. Also, when a child had a brother or sister in hospital, the sibling had plenty of anxieties.

Dr. Earnshaw said it was her experience that children feared their wishes to damage or even exterminate rivals had actually caused things to happen. If these intense and disturbing feelings could be talked about and shared she felt they were less likely to reverberate at the anniversaries of the disturbing events.

The speaker's general hypothesis, based on years of observation and asking, was that most people experience reverberating life events when they reach the ages their parents were when the shared events of their childhood occurred. She felt an individual was to some extent in step with a parent, usually of the same sex, in the timing of his/her own life events.

Dr. Earnshaw concluded her contribution by saying that considering the 'when' of events from the point of view of shared anniversaries could relieve otherwise incomprehensible states of confusion and perplexity. Perhaps some illness might be thought about as a demand for attention by the family, and she felt it gave others a chance to join the family and break what might be a vicious, reverberating circle.

Miss G Meers, Nursing Officer; Miss W Rockhill, Ward Sister; Mrs Lewis, Liaison Health Visitor; Mrs S Howarth, Play Co-ordinator; and Dr S Chong, Research Fellow and Honorary Senior Paediatric Registrar, St Bartholomew's Hospital, (formerly at Roehampton).

Practical viewpoints from Queen Mary's Hospital, Roehampton

Slides taken from the film 'They're Children - They're Different' were used to illustrate this presentation.

Mrs Lewis began by explaining her role. She visited the ward daily to discuss children who had been admitted or were being discharged and any problems arising in the ward or community. She relayed information to the health visitors and obtained information from them about family backgrounds. She also visited the Accident and Emergency Department daily and followed through to the ward those children who had been admitted. Other cases were selected which she felt the health visitors should know about. Mrs Lewis stressed that she did not come between health visitors and hospital staff who did, of course, communicate directly.

Mrs Howarth, Play Co-ordinator, spoke of her work in the out-patients' Play Area. She said that out-patients was very often the child's first sight of the hospital and it was important for this to be a good and a learning experience. She tried to provide a link for the children by seeing them in the out-patients and on the wards. She also took the children coming to out-patients to the wards and showed them round.

Miss Meers stressed that a play service must not be used as an excuse for not improving long waiting times in out-patients. Mrs Howarth agreed that sometimes she felt she was protecting doctors from parents who would otherwise complain about their long wait, and that perhaps she was propping up an inefficient system by making the waiting less difficult. Dr Chong said that when the childen played out the roles of doctors etc. this acted as a displacement of their fear of the situation they were in.

Mrs Howarth continued that in Ear, Nose and Throat Departments, where she had worked for six months, audiologists and found their job much easier since she had been there, with the children being calmer and more co-operative. Mrs Howarth went on to say she did not consider the job of Play Co-ordinator a suitable one for a young nursery nurse. She felt, in the case of her own out-patients' department, it was a very small constricted area; people were waiting a long time and there were tense children after a long wait.

The Chairman posed the question of why did the parents and children have to wait so long in out-patients, and said this was an overwhelming message that came out in the Consumers' Association Report. This, he said, was a matter of organisation.

A slide was then shown of the admission of a child to hospital with his mother and father, and the importance of welcoming the child and finding out his likes and dislikes, e.g. diet, was emphasised. Miss Meers felt we should be asking whether any children admitted could be nursed at home. A case was then illustrated where an elder sister was admitted with an ill baby because the mother was torn between her responsibilities to both children.

A discussion then followed on uniform, prompted by a remark from the floor. At Roehampton coloured tabards were now being worn in place of aprons. The Play Co-ordinator commented that children who had been prepared for hospital expected to see a nurse in uniform, and if they found nurses not in uniform they might feel this was not right. The Ward Sister said that student nurses wore very elaborate caps and the children wanted caps like these made out of paper for them. The fact that the uniform was protective clothing was also mentioned. A floor speaker commented that she worked in the Community and felt she was admitted more readily into houses because of her uniform.

The question of problems arising when siblings were allowed on the ward was then discussed. The Ward Sister said it could be difficult when there were large numbers of siblings on the ward, and that most of the damage in the playroom had been caused by the siblings. She stressed control of them was not usually a problem. The Nursing Officer said that sometimes the visiting child needed to be organised to play a game with the sick child and not be allowed to use the ward as a playground. The Play Co-ordinator said this was sometimes her role and also there were times when she would occupy the siblings so the mother could be with the sick child. It was generally felt that infection from siblings was not a problem although, obviously, on infectious diseases wards, for their own safety, there would be restrictions on siblings visiting. A Roehampton older siblings were often resident with a young child, which made the child happy and took some pressure from the mother. It was felt also, that it was beneficial to the siblings to be involved in what was happening to the sick child.

The Nursing Officer quoted an example of an eighteen year old spina bifida patient who spent a long time in hospital and was being allowed to have his birds in because he missed his pets more than anything. Professor Oppé stressed that we must be flexible and there were cases where we must individualise. Occasionally it was very important to allow children to see their pets. Also he felt the same applied to best friends and that it was important for children to keep in contact with their peer groups.

Dr Chong stressed two factors when examining children - the importance of coming down to the child's level by crouching, and the wearing of mufti and not a white coat. He also mentioned that he always carried a toy in his pocket - this was something a child could associate with and which would help him to look upon the Doctor as a friend. Professor Oppé commented that instead of getting down to the child's level, alternatively, the doctor could put the child up or above his level.

A final contribution from the team was when 'pain' was discussed. Dr Chong felt it important to explain to children if they were going to feel pain during a procedure. The presence of mother and a nurse familiar to the child was often very helpful at such a procedure. The Play Co-ordinator said she would be present at those times if necessary and if the child wanted her - she was not the eternal 'goody' who did not get involved with painful procedure. Dr Chong also felt there should not be a 'baddy' and it would not help the child if he were considered as such. The person to be at a procedure or taking a child to theatre was the one the child wanted.

CHAIRMAN'S SHARING OF GROUP DELIBERATIONS

During the last session of the day Professor Oppé reported on the groups' deliberations during syndicate discussions.

Question A

The Consumers' Association report says that:

> 'Parents need more information about the practical aspects of hospital stays. Special leaflets should be issued and more thought given to content, layout and production.'
>
> In another part of the report it is said that:
>
> 'in two-fifths of hospitals children are not allowed to visit brother or sister in hospital. It should be possible to cope with overboisterous children without preventing all children visiting.'
>
> Can the group devise a leaflet (headings only) detailing those aspects about which parents need information in order to prepare themselves and their children for admission?
>
> Also, can the group suggest ways of how the rule related to siblings visiting might be relaxed and suggest ways of coping with overboisterous children?

Two major issues were discussed - the problem of sibling visiting and the problem of leaflets. Sibling visiting had already been adequately discussed at the Conference and the group did not add much to this except to positively reiterate that sibling visiting should be encouraged.

The group felt leaflets were helpful and it was worth spending time and trouble in their preparation. They felt more could be done to distribute leaflets more widely in doctors' waiting rooms, etc. The group considered that visual material was very valuable in leaflets, especially in areas where, perhaps, little English was understood. Professor Oppé said one suggestion from the group which rather alarmed him, was that mothers leaving maternity hospitals should be given leaflets preparing them for the admission of their baby to hospital!

Question B

The Consumers' Association report says:

> 'The physical presence of the child's mother was of enormous importance. All children longed to have their mothers with them and became very depressed and lonely when the mothers had to leave. This feeling was particularly acute at night and was not confined to the youngest children. Not only did mothers provide emotional support but they were a critical link with the child's normal life and could deal, on the child's behalf, with the adult hospital world'......'The presence of mother has, since Platt, been recognised as being of paramount importance to children.' 'Some hospitals have accepted this and parents have become a central feature of hospital routine. In others only lip-service has been paid to the idea and, parents are discouraged or admitted grudgingly, even where facilities exist.'
>
> Can the group suggest the best ways of identifying and helping parents to undertake a practical role in caring for their children in hospital?

Professor Oppé felt that all those concerned in the Consumers' Association report must find it difficult to understand why, when the policy of unrestricted visiting and staying in had been stated so clearly in the Platt Report and since, nevertheless, there was indisputable evidence for this in the Consumers' Association report that in far too many places only lip service was given. There was pretence that parents were encouraged to visit when, in fact, this was not so.

Unfortunately Group B avoided the issue and spent their time discussing the problem they met in persuading mothers to stay in. However, they did feel, where there were difficulties about the admission and welcoming of mothers, it was probably not the nursing staff who were largely responsible. They felt there was now overwhelming support on the part of nursing staff for the admission of mothers, unrestricted visiting, and the participation of mothers in the care of their children. They felt it was the medical staff, especially those dealing with adults and not children, who were the most difficult. Professor Oppé agreed there were difficulties for nurses and paediatricians persuading their colleagues in adult medicine to see the importance of these issues.

Question C

Concerning out-patients and accident and emergency departments the report says:

> 'More hospitals need to conform to DHSS policy and see children separately in out-patients and accident and emergency departments. Child patients (and their parents) spend a long time in these departments yet little is done in them to reduce children's apprehension, particularly when adults are present or staff have not been paediatrically trained.'
>
> How might the apprehension of children be reduced? How essential is it that such staff be paediatrically trained? Is this need to conform a viable one? How might the adoption of such specific facilities be encouraged in hospitals which lack them?

There were only two people in the group who were expert and worked in out-patients or Accident and Emergency Departments.

They felt it was important that, where possible, there should be segregation of child patients from adult patients, both in Accident and Emergency Departments and in Out-patients. They considered separate waiting rooms, separate consulting rooms and play facilities were important. However, they wondered if such facilities were viable with the present strained resources, and felt that possibly this was not an area of very high priority.

With regard to trained paediatric staff they thought it was desirable to have some around. If they were in position of leadership they could provide a good influence on those without paediatric training. An interesting point was, that in Out-patients, because of the hours worked, there tended to be married nurses with children of their own, and the group felt child rearing was some sort of equivalent to a paediatric training with regard to sensitivity for the care of parents and children.

Another point was that in an Out-patients or Accident and Emergency Department in adult hospitals, even if segregation was available in these departments, de-segregation would take place in the back-up departments such as X-ray.

Question D

The Consumers' Association report says:

> 'Hospitals were not always sensitive enough to the emotional problems associated with discharge. As social workers are not involved with all patients it might be useful to train hospital staff to identify the beginnings of emotional problems which might develop when a child reaches home. Discussion with parents about this should be part of hospital routine and it would be convenient to give general advice on paper.'
>
> Can the group suggest ways in which staff might be trained to identify the beginnings of such problems and how parents might be supported?

The group felt that emotional problems could not be identified early unless there were good communications among all those working on the ward, with the child and the parents. They felt there should be an identified person who played a major role in spotting the beginning of emotional problems. Also there should be a deliberately arranged conscious team approach to the problems and that, if this happened and the ward team met to discuss children and parents, then almost always these emotional problems or the likelihood of an emotional problem would emerge from the discussion.

The point was also made that such team discussions were not only useful for identifying problems but could act as a support system for the various members of the team who were challenged or apprehensive about emotional difficulties and problems.

Question E

Concerning patient assignment the report says:

> 'More paediatrically trained nurses are needed. Patient assignment is given fairly low priority in a large majority of hospitals and is seen by some ward sisters as something which slows down the progress of what they sometimes tend to regard as the real work.'
>
> Should patient assignment be encouraged? If so, how? If not, why?

The group agreed that patient assignment was a very good thing. They made the point that where there was patient assignment the young and inexperienced nurse was more likely to be exposed to emotional involvement needing support herself, and that this was possibly one of the problems with this type of care (patient assignment), and that to be practised effectively a support system must be available.

The group felt that the support system should be provided by the nursing profession, and there was discussion as to whether the ward sister should be responsible for this or whether the School of Nursing had a role to play.

Question F

Concerning arrangements for children whose parents cannot visit them, the report says:

> 'Hospitals should make much greater efforts to help parents who are 'torn between home and hospital'....'they should counsel parents on the best way of coping with problems at home while spending as much time as necessary with the child in hospital. It should always be possible to bring brothers or sisters into hospital and they should be able to stay in when necessary. The DHSS recommend that parent/child rooms be available for long or short periods and, overnight accommodation for visiting parents and brothers and sisters who have to travel a long way to the hospital.'
>
> How are such parents to be helped? Are the recommendations and suggestions tenable?

This was in some ways considered a community issue because the better a family could know about the admission of a child to hospital and the ways they could plan, there would be fewer problems when the actual crisis came. Good planning was necessary and possibly Health Education had a role to play. Health Visitors were important in this issue. At all times there must be an intense awareness of the uniqueness of family life and that the problems in each family were different from others, and there could not be a simple standard solution.

Paediatric liaison systems were praised. Liaison should not only be concerned with transfer from hospital to community, but also there should often be better liaison for transfer from the community into the hospital.

It was suggested that buildings and accommodation were not all-important but more important were the attitudes of the staff and the willingness to 'make do' and adapt.

The Chairman then brought the conference to a close. He stressed this was the beginning not the end. In some areas there was a lot to be done, those pinpointed in the Consumers' Association Report as lagging behind in good practice. There were always difficulties not only with money but in attitudes; work patterns and administration also prevented the policies being put into practice.

Professor Oppé hoped that those present at the conference would go back enthused and prepared to carry on the struggle, in order to achieve better practices. He hoped that those who came from places with good practices would go back and see whether further improvements could be made and whether some policies had become entrenched and inflexible and should be reviewed.