King Edward's Hospital Fund for London

The King's Fund Centre

# THE CONTRIBUTION AND NEEDS OF THE NURSE CARING FOR SICK CHILDREN

Report of a Conference held at the King's Fund Centre
held on Tuesday 11 September 1979

Report by Diane Sayle

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

# THE CONTRIBUTION AND NEEDS OF THE NURSE CARING FOR SICK CHILDREN AND THEIR FAMILIES

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On 11 September 1979 a conference was held at the King's Fund Centre, London, entitled "The Contribution and Needs of the Nurse Caring for Sick Children and their Families"

Those present were welcomed to the Centre by the Director, Mr. Graham Cannon, and he then introduced the Chairman, Professor F.S.W. Brimblecombe, C.B.E., M.D., F.R.C.P., Professor of Child Health, University of Exeter.

Professor Brimblecombe said the conference was a day for discussion and interchange of ideas. He spoke about the work of the Children's Committee, of which he was Chairman. This was set up about one year ago to advise the Secretary of State for Health and the Secretary of State for Education on the development and co-ordination of health and personal social services as they related to children and families with children. On the Children's Committee there was an Area Nurse Child Health, Joan Smith from Birmingham, a strong representative and advocate of Children's Nursing. One of the first initiatives the Children's Committee took was to draw the attention of the Secretary of State to the enormous concern about children's nursing in this country, and the tremendous need for more training in children's nursing, both in hospital and in the community. The Committee was as much concerned with the amount of training given to health visitors, district nurses and midwives as with the training of nurses working with sick children in hospitals. The Committee was appalled at the decline in the number of nurses on children's wards who possessed the Registered Sick Children's Nurse qualification. The Secretary of State's attention was drawn to this and the situation was being discussed.

The Chairman then spoke of 'The International Year of the Child' and he asked those present what they thought had been achieved in this year. He pointed out that there had been many conferences but wondered if anything had really been accomplished. He felt Europe had gone much farther than Britain in its achievements for IYC, and told the conerence of the journal called 'The Health of the Infant and of the Family in the Fourth World' (La Revue de Paediatrie - La Saute de l'enfant et de la famille en quatre monde).

This Journal was produced by the International Children's Centre in France and was a product of IYC. The Fourth World was the world of underprivileged families - the group which in many areas we had failed conspicuously to help. These families started the cycle when the mother did not attend the antenatal clinic, reported her pregnancy late and was ill-prepared for parenthood. From there evolved the cycle of underprivilege. It was not just a question of amount of wages or husbands' occupations -

there were many factors involved. The Committee was sorry that there were so few British contributions to the Fourth World Journal. Professor Brimblecombe felt it was very exciting that all over Europe effort was being made to identify much more precisely the characteristics of the individuals who made up the fourth world. There were two million such individuals in France.

Concerning infant mortality and perinatal mortality, it was known that Social Class 5 did disastrously worse than Social Class 1 - their use of hospitals was so often inappropriate. Ways must be found of reaching the Fourth World and this was very difficult. These families needed the service most but made least use of it. To reach these families had become the crusade in Europe during IYC, and the Chairman was very impressed by this, feeling it had relevance to the Conference. The Journal was written in French with English résumés of every article.

The Chairman then introduced the first speaker, Mrs. J. Gardner, Senior Tutor, Brighton District School of Nursing. Her subject was 'The preparation of the nurse working with children'. Working with nurses over the years she had found ward staff were expecting more and more of the young learners. Mrs. Gardner said when she had trained in the late 1950's nurses knew what they were - the lowest form of life - but they were not expected to know anything further. Mrs. Gardner compared this with what a young nurse had told her recently - that she had done a 'sham' feed after one week on the ward. There were other difficulties. Whereas the speaker had never had to cope with parents until her third year, a young nurse today was put into a cubicle to nurse a sick child and the parents were present. There were big advancements in treatments, surgical techniques and psychiatric care for children. The role of the paediatric nurse had been influenced by all this - she was now a member of a team - a team who worked with members of other professions for the welfare of the child and his family. She no longer replaced the mother in the hospitalised child's life and she must now be prepared to help the mother care for her child when well or ill. The nurse must recognise the child as an individual, a member of a family and a community.

It must also be remembered there was a change in the people doing the caring. Once there were a lot of R.S.C.N. learners. Now much caring was done by seconded pupils and students, and the speaker felt these nurses were not always given enough attention and preparation. There was a shortage of trained RSCN's and a lack of trained paediatric tutors, so the preparation of learners was limited.

The nurse was being prepared for a unique experience. The age range she would care for was 0 - 14 or 15 years. The anatomical, physiological and psychological differences of that age range must be considered, and also the comparison with the adult patients she had nursed so far. Mrs. Gardner then looked at what the nurse would be expected to cope with, such as the sick, irritable child, and the anxious, perhaps aggressive, parents who watched the nurse with critical eyes (at least they would feel critical to the nurse). She must also learn about the isolation of cubicle nursing. Many nurses found this very hard. No longer were there colleagues to talk to; just the child and perhaps the parents. Another problem the nurse must face was what to say to the parents. This must be discussed with the nurse before she was put in the cubicle with the child, otherwise she might become frightened and the mother and child might get inadequate care. Also the nurse might find difficulty in approaching the child in a calm and friendly way. She had to use touch, which was not used much in adult nursing, and tone of voice to calm the patient. She must be confident of the observations she was making and she must be encouraged to report changes even if they seemed very insignificant. The nurse in the paediatric situation had to cope with patient allocation, so she had to deal with the doctors and perhaps with questioning from the Consultants.

Mrs. Gardner then considered how some of the problems she had mentioned might be dealt with. First, she felt that the individual must know the situation within his/her own district. The nurse must be encouraged to discuss her own anxieties - for example, she might not like children or babies, but the General Nursing Council stipulated eight weeks' experience in paediatrics. The nurse must be told and helped to get to know child she was caring for. It was very important to get to know the patient and it must be stressed that this took longer with children. She had to gain the trust of the child. The nurse must be allowed to learn what information she could give to parents. Mrs. Gardner said that when she was a ward sister the words 'comfortable' and 'satisfactory' were forbidden. The nurses had to give a message about the child, for example, 'He's eaten his breakfast' : He's grinning'. The nurses were always encouraged to find out when parents were returning and to make clocks for younger children which could be compared with the clock on the wall, so the child knew when Mum was coming back. Nurses must be taught to listen and this was difficult. They must listen to changes in respiration, change in the noise of apparatus, and the whimpering of a child, either from physical or emotional pain which must be releived. They must listen for the child who only whispered for his potty. They must learn the child's language. The nurse must also look - she must notice the child who would not smile and ask why. He must not be labelled a naughty child.

In summary, the nurse must be helped to cope with her own feelings about children, with death and dying, with complex as well as simple skills. She must look and listen. The most difficult aspect to teach the nurse was how to show the mother to care for her child.

Mrs. Gardner said that when discussing their preparation with some student and pupil nurses doing their paediatric secondment, the following points had emerged. There was a need to adapt procedures to fit the child, e.g. aseptic technique. This emphasised the fact that principles, not procedures, must be taught. Also the problem of terminal illness must be discussed. The nurses asked what could be said to a child who asked if he was dying. The nurses felt, too, that they were not given long enough to establish a relationship with the children, and this aspect had not been stressed enough.

Mrs. Gardner concluded by saying she believed the contribution of nurses towards caring for sick children could be much greater than at present if we considered more carefully their preparation for this role.

The Chairman asked Mrs. Gardner how much she felt could be taught in eight weeks. She said a lot could be taught about attitudes. One of the areas where there was failure was in putting a nurse into a situation and expecting her to cope without preparation. The nurse should work with other nurses on the ward before she worked with a child, and be given time to observe and to work under supervision. Also, perhaps a nurse should be given longer caring for one child instead of being moved among many children to gain a wide variety of experience.

The next speakers were a team from the Westminster Children's Hospital, and their subject was 'Counselling and Support for Nurses and Patients' Families'. Dr. Graham Watson, Honorary Lecturer, began this session. He explained that he would use the bone marrow transplant programme as an outline of the stresses and strains on nurses and doctors, families and other children. The indications for bone marrow transplantation in childhood were the severe congenital immune deficiencies, aplastic anaemia, and, increasingly, leukaemia. Marrow must be taken from a donor, almost always a brother or sister. The amount of marrow required varied from ten ml. to one and a half pints. The bone marrow was given intravenously to the recipient. In certain cases the graft attacked the patient, frequently killing him. This could lead to guilt feelings in the donor. About one third of the recipients were affected by this, and one half of these died. Also, it could be a chronic disease which continued, perhaps for years, with the same psychological strains arising. Infection was a major hazard, too. Dr. Watson showed a slide of a boy with chicken pox. He was an elective transplant, well known to the nurses over the preceding years and this posed additional strains on the staff. In an attempt to exclude infection risk from these very vulnerable patients, plastic isolator tents

tents were used which required adaptation in nursing techniques. The tent could be situated in the ward so that the child could take part in ward activities, and parents could play games with their children. Babies had smaller isolators and very good observation was possible. Finally, Dr. Watson showed a slide of two successful transplant patients raising money at a local fête - much transplant work being done on charity money. He concluded by saying that the survival rate was fifty per cent.

The next speaker - Miss Dunne, Senior Nursing Officer (Paediatrics) - continued the theme of bone marrow transplants. She said that as these transplants were a relatively new procedure a rather structured pattern had evolved, and it was very much a team effort. She went on to describe the meetings that were held to illustrate the support that could be derived from a cohesive team committed to the work being undertaken. The largest meetings were those held weekly for one hour at lunch time. These were attended by the medical and nursing staff, dieticians, physiotherapists, pharmacists, and haematology and bacteriology technicians. A background of each patient was given, the basic disease, the progress and laboratory results, and each discipline made a report. Miss Dunne said there was considerable nursing input to this meeting, and the meeting definitely increased efficiency. On the ward there were Thursday meetings to discuss weekend cover. The Psychiatrists had been very helpful to nursing staff, families and children and had become very involved. The Child Psychiatrist met with the nurses and discussed the patients. Other meetings were held with the Chaplain and a very experienced medical social worker. The team of nurses was supported by nursing officers. Some of the particular areas of stress already mentioned were the uncertainty of infection and the individual's worry that she might be the one to introduce it into a sterile situation, and the thought of the graft versus host disease which was unpredictable. The nurses became closely identified with parents and children, and wanted to protect the children from traumatic procedures such as bone marrow aspirations. The nurses were naturally distressed if these procedures seemed to take too long, or were not done as expertly as possible. The children became dependent on particular nurses, asking a nurse to change her off-duty to help them through certain procedures. This put a strain on the nurse. Sometimes she had to be persuaded to go on holiday which she might want to postpone until a particular child was better. Another area of stress was the staffing shortage.

The nurses continually needed help to understand stress. The nurse was given a lot of confidential information, for example, from parents with marital problems. She could turn to the psychiatrist or medical social worker for further help, and might learn a great deal herself in doing so.

The nurse needed a lot of support in understanding her role in relation to the mother. Some parents cared almost totally for their children, whereas some children liked the nurses to bath them and their mothers to watch. The nurse must be ready to adapt to whatever the mother felt able to do. Miss Dunne said the child in hospital was not a special creature but one with a total life picture behind him and who for a time needed attention. Increasingly, both parents were staying with their children, and they were encouraged to be continually involved in the children's care. The mothers needed a rest at times, and must be reassured that the nurses would try to fulfil their role when they were not there. Nurses must be wary of forcing parents into situations which they were reluctant to take on, and, as said before, the child often knew what he wished his nurses and not his mother to do for him.

Parents were encouraged to develop surrogate roles with other children in the ward. These children became very fond of mothers who were in the ward for many months. Teachers, play leaders, and nursery nurses were also involved with the children in cubicles and isolator tents, and the parents appreciated very much this degree of normality in the children's lives.

Parents were told the absolute truth from medical and nursing staff, and hopefully the weekly meetings ensured that everybody was giving the same information to the parents. Over the months the parents became very knowledgeable and some nurses felt threatened by this. Miss Dunne said it was a very good lesson for the student nurses to learn to listen to the mother.

The work demanded a lot of discipline, e.g. getting children to take medicines, and the organisation of items to be introduced into the sterile environment. Miss Dunne said although Christian names were mostly used in the wards, which the parents seemed to appreciate, nurses needed to remember their role as deliverers of care and not become dependent on their patients. Nursing had always been a stressful occupation. Death was saddening for those who had put so much effort and time into saving lives. But Miss Dunne felt we had learnt from our predecessors, who had dealt with another group of children -

the multiply handicapped - to ensure that a patient had a dignified death. Some of the rewards, seen on Dr. Watson's slides, were very good for the morale of the whole team.

The next speaker was Rev. David Stoter, Chaplain, Westminster Children's Hospital. He said he would try to highlight some of the problem areas for relatives, although he felt the most important aspect of the conference was the needs and training of the nurse. But, of course, the relatives affected the nurse.

When a child was admitted into a high stress area, for example, for bone marrow transplantation or into an intensive care unit, there was, almost invariably, a great deal of fear. Often a grave diagnosis and prognosis had been presented to the parents, and this had turned their lives upside down. Their whole attention was focused on to this child and this situation. Priorities altered, and ways of responding and reacting altered, and people who would normally be very helpful and co-operative could be quite the reverse for a time - angry, unco-operative and paranoid. Often they needed a great deal of understanding, because the first reaction was to think 'This is a difficult parent who must be contained in some way'. This could be the start of a slippery slope. We needed to understand what the parents were feeling and how they were responding. Rev. Stoter suggested this did not only apply to high pressure areas. Parents could be very stressed when children were undergoing minor surgery or procedures.

The parents felt they lost their role when their child entered hospital: the experts were taking over his care. The parents could feel they were onlookers. This was frightening and made parents feel insecure. They did not understand what was going on inside them, and why they were responding as they did, in a way foreign to them. They might begin to relate badly to one another, because in a high pressure situation a person tended to snap at someone close to him. This difficult situation could be made worse by talking to one parent and not both. Rev. Stoter believed it was very dangerous to talk to Mum and ask her to tell Dad. Dad could feel he was just an appendage, rather than a vitally important person, and that it was good enough for him to get second hand news (which could become distorted).

So, important issues were, to enable the parents to rediscover their roles, to be able to relate to their child, to still be the parents, to learn how to be the parents in a strange environment. Sometimes it was necessary to take the responsibility from them to enable them to withdraw for a while, but then they must be helped back into the situation to carry on again. Also, they must be helped to understand the emotions that they and the child were experiencing. The parents needed much preparation.

Rev. Stoter then spoke about staff needs. All the pressures that were on the parents came on to the staff. This especially applied to the nursing staff who were there all the time, and particularly the junior staff who were often first at hand, and they needed a lot of preparation. But it was not enough just to prepare them, they must be supported when difficult situations arose - teamwork was vital. The nurse needed to know she could turn to someone and get support. The ward meetings were essential, and the atmosphere must be such that everyone felt he/she could speak openly. Also it needed 'enabling' - someone must feed in the sort of problem areas that were developing. Rev. Stoter felt these meetings should be separate from the School of Nursing. Nurses often said they would rather not have tutors and clinical instructors present - they did not want to feel they were being marked. The nurses felt they could reveal their needs during the meeting to sisters and staff nurses, as they were also involved in the same problems and had often revealed their needs too. Often when a nurse realised the Chaplain or Child Psychiatrist or another member of staff would listen to her she would approach them and talk of her fears and feelings. Rev. Stoter felt he had a role with his collar on and also with it off. Sometimes he needed to be seen as a person to listen to anxieties, and sometimes as a chaplain who could speak in a particular role. The group meetings could be very heated. The nurses had to cope with the ambivalence of what the doctors were saying about the treatment, and what the parents and child were feeling about it. The nurses identified with the feelings of the parents and the child, and sometimes got very angry about a decision to do more treatment when they wanted it to stop. There was also the very real problem of coping with the beginnings of bereavement that came and went in the parents. Sometimes the parents would grieve for a child they expected to die, and then be filled with hope again. This was very difficult to cope with. The nurse could become very obsessed and introspective about her abilities as a nurse to cope in this situation of tight stress where she was working with one child or two children and their families.

Rev. Stoter concluded by speaking of the very great need for support of staff at all levels, not only nursing staff but medical, physiotherapists, dietitians and other staff as well. A support system should be implemented on every paediatric ward, and chaplains and child psychiatrists should have time to go to ward meetings and time for the needs of staff and relatives. This should be written in their job descriptions. He felt time off for minor ailments such as colds was much higher when there was a load of stress which was not being dealt with.

The next speakers were a team from Birmingham, and their subject was 'Preparing to nurse the child and family in the community'. Miss Howell, Nursing Officer (Community Nursing), began this session by talking about the nurse and her role in the Birmingham Children's Unit, which was community based.

The Paediatric Community Unit, when fully staffed, was comprised of five State Registered Nurses, each holding the RSCN qualification. The job description of these nurses was as follows. To work as a member of a team caring for acutely and chronically sick children; to provide support and skilled advice to parents; to teach and supervise the nursing care a family could safely assume; to interpret to parents the implications of diagnosis; accurate observation of physical and mental conditions and referral as necessary; close liaison with hospital colleagues, G.P's and other services; knowledge of equipment available to enable the child to be nursed at home; health education and promotion of the work of the unit; to meet the needs of the students and visitors and to maintain accurate records.

To obtain the National District Nursing Certificate the nurse must undertake four months' training, as the general nurses did. She would be placed with the general district nurse on the area with the children's unit. There she was supervised by a practical work teacher, learning to adapt her skills to the home situation, and learning of the community services. At this time her case load would be adult patients.

At the end of her training the Paediatric District Sister was given two weeks' experience at the hospital to which she would be attached. She was taken as an observer with a Paediatric Community Sister and built up her case load routine from there.

Miss Howell then showed some slides of a child, followed by a tape. The child, born in 1970, had a hare lip, cleft palate and imperforate anus, and her eyelids were barely open. Her mother was congenitally deaf and her father was deaf at the age of five, following streptomycin injections. The Paediatric Unit was called in to help. In the first two weeks the mother had six hopsital appointments, and the Deaf Association transported her to these appointments. The district paediatric sister visited two or three times daily. Miss Howell recounted the child's progress through various operations. A tape was then played in which the child and her mother spoke of their experiences.

The next speaker in the Birmingham team was Miss K. Knowles, Paediatric District Sister. She explained that the Paediatric Unit started in Birmingham in 1955, before the time of free hospital visiting and the five day wards. It was set up after talks with the Children's Hospital and the Consultants and the Local Authority. Two District Nursing Sisters with experience in the care of children were chosen to pioneer the Unit. By 1962 a fully comprehensive twenty-four service was available. The five Paediatric District Nursing Sisters now involved in the scheme were each hospital attached. Patients were referred direct to the Unit. Regular meetings were held to discuss the patients. The sisters were also responsible for students.

Miss Knowles then spoke of liaison. Patients were referred from the hospitals, parents, general nurses, health visitors, G.P's, social workers in the Special Schools and school nurses. The Unit fitted into the general home nursing service with such services as loans, domiciliary laundry, night watch, home helps and Marie Curie.

The Aims of the service were:-

1) To keep the child amongst his family
2) To reduce the necessity for admission to hospital - especially for chronic illnesses e.g. chest infections.
3) To facilitate earlier discharge from hospital
4) To improve the quality of care
5) To seek early medical attention
6) To shorten the duration of illness
7) To take advantage of opportunities for health education
8) To provide support to child, parents and family
9) To help the child achieve his full potential
10) To teach students who attend for observation visits.

The Advantages of the Unit were:-

1) Avoidance of undue separation of child from parents and family, and possible psychological upsets.
2) The family became actively involved in the nursing care of their child - they knew they were giving a real contribution to his recovery.
3) Convenience - no need for the whole family to be organised round visiting hospital
4) Saved many costs that hospital visiting entailed
5) Saved use of hospital beds
6) Prevention of contact with hospital infection
7) District Nursing Sister acted as point of contact between home and hospital.

The need for such a Unit was shown in the following ways:-

1) Staff were never without a daily case load.
2) An increase in the standard of living - better facilities - parents more able to cope in a family unit.
3) With increasingly sophisticated treatment, drug therapy and equipment, the general nurses did not also feel able to cope in the paediatric area.
4) Some paediatricians would not discharge a child unless into the care of Unit staff
5) Mothers continued to say the Paediatric Unit was indispensable.

Changes which had influenced the work of the Unit over the years were the massive rehousing programme, the increase in the number of immigrants and the increasing survival of handicapped children. There were also now earlier hospital discharges, the invention and availability of aids and the introduction of attendance and mobility allowances.

Miss Knowles then described her work. She carried out treatments such as injections, dressings, care of stomas and care of traction. She gave support and nursing care to patients with acute illnesses and infectious diseases. Those with acute exacerbation of chronic illnesses and the mentally and physically handicapped were also nursed and supported by her. She also cared for the terminally ill, and patients with psychological disorders. Miss Knowles gave practical and financial advice and referred to other agencies when necessary. The parents were taught to carry out as much care as possible.

Miss Knowles concluded her talk by stating the overall aim of the Unit. This was the restoration of independence and full living for the child and family within whatever limitations were presented, through the medium of acceptability, security, encouragement and support. Also to reassure the mother and family that the nursing staff believed in their adequacy as part of the team in nursing their sick child.

Miss Knowles then showed slides of patients to illustrate the work she carried out.

The final speaker in the Birmingham team was Miss P. Davies, Health Visitor, West Birmingham Health District. She spoke of the Health Visitor's role in the Paediatric Unit. Miss Davies worked in a Health Centre attached to a group of five general practitioners and was a member of the primary health care team at that centre.

The role and function of the health visitor was:-

1) Prevention of mental, physical and emotional ill health.
2) Early detection of ill health and surveillance of high risk groups
3) Recognition and identification of need and mobilisation of resources.
4) Health teaching
5) Provision of care - support during stress. Advice and guidance in illness and the management of children.

Miss Davies stressed the importance of prevention, an area where there was little praise because what had not occurred could not be measured. She asked whether we should be concentrating more on the ante natal period, and looking at the risk groups more carefully - the unmarried mother, the late booker, the schoolgirl mother.

Miss Davies then compared the roles of the health visitor and nurse. Like the district nurse the health visitor undertook much of her work in the home, and for the health visitor the Clinic or Health Centre played an important part, too. For the health visitor sick children were just one aspect of her total work. She was promoting health as opposed to dealing with sickness. She was an advisor rather than a practical nurse, but, of course, had a background of nursing knowledge and skills, and midwifery or obstetric experience.

The Health Visitor was an SRN and SCM (or had obstetric experience) and she took a twelve month course. She was placed with a field work teacher for practical work and also carried out three months' supervised practice.

The Health Visitor had a statutory duty to visit all children in a geographical area or on a GP attachment from birth to the age of five years. So she had knowledge of all sick children on her case load.

Miss Davies spoke of the importance of keeping the chronically sick child as 'normal' as possible - not to miss out on routine developmental screening, hearing tests, orthoptic appointments and particularly immunisation.

The Health Visitor was involved with arranging services such as voluntary agencies, self help groups, groups for the handicapped, care and assessment units, nurseries and playgroups. Since 1973, in Miss Davies' district, there had been peripatetic teachers visiting 0 - 5 year olds and instructing parents how best to stimulate their children, and how to play with them.

Hospital liaison was important and must be a two way communication between health visitors and hospitals. The Health Visitor must observe sick children in high risk groups, e.g. the parents with low I.Q., social problems, handicapped, immigrants. Miss Davies believed a health visitor could not work with new immigrants without an interpreter.

The needs of the Health Visitor were:-

1) Understanding of her own role in the primary health care team. This was important because the health visitor could be pushed into many activities which were not her role.
2) Communication with hospital and medical colleagues. The Children's Nursing Unit issued a weekly return with the name, address, diagnosis and treatment of the children they were currently visiting and this was most useful. There must also be communication with Social Services, Education Departments, and Voluntary Agencies.
3) Support from nursing management, and from colleagues.
4) Refreshment. It was important for the health visitor to keep up to date, to be able to go for regular study days and to meet people of other disciplines.

After lunch there were group discussions on arranged topics and significant points were reported back to the conference as follows:
Question:
Preparation of the child and family either for emergency or planned admission to hospital should be considered part of the ordinary preparation for life, in much the same way as sex education is widely accepted. Can members of the group suggest ways in which this can be achieved?

The preparation of child and family for hospital admission was a task of general education. Project work could be done by schoolchildren concerning this and the children could participate in discussions.

Collages could be made by schoolchildren and displayed in nursery schools and outpatient areas.

Older children (fifteen/sixteen year olds) could be educated about hospital admission as part of their preparation for adult life.

Antenatal and postnatal groups could have discussions about this. Children could visit hospitals and look around. Television could be used for discussion on this subject. Children could participate in role play.

Question:
Some children are still being cared for in adult wards. If this is a necessity, what can be done by the staff to reduce the problems which arise for the child, the family and other patients in the ward?

The Platt Report had not yet been fully implemented. It had been policy for many years that children should not be nursed on adult wards. The provision was there - there were beds in children's wards not being used - so there must be better planning of health care facilities.

Nurses must insist that children were not nursed in general wards - nurses had a unique position from which to say this.

It was suggested that a joint advisory committee might be set up with other professional colleagues. It was felt a time limit should be set out that beyond this time children would not be admitted to adult wards.

If children must be nursed in adult wards they must be given adequate support: have a separate play area and play worker. Also they should have paediatric nurses to care for them.

Open visiting must be allowed.

Question:
There is increasing recognition of the stress involved in the care of sick children and their families. Can members of the group give examples in which they have sought to modify this and to make use of it as a learning situation?

Two examples were given.
Firstly, the stress of a father becoming emotionally involved with a trained nurse on the ward. A great stress situation developed between the whole family and between the staff and the family. A Staff Conference was called, and the psychiatrist invited to attend. Then the family was invited to see the psychiatrist. The mother was very dependent on the ward and it was decided to wean her away to more independence, to help stabilise the family unit.

It was felt that learners could be shown that from this tangle they could look much deeper into the situation.

Children were an emotive subject and staff on children's wards very vulnerable. Learners should be fully aware of the emotional entanglements of children's wards.

There should be more use of professional counselling - psychiatrists, clergy, senior staff.

Industrial relations and discipline were also discussed. The example showed how easily a stress situation could build up and intensify before anyone realised how serious it had become. The family was reconciled with the help of the psychiatrist, and the nurse left the ward. The child was

now at home within a complete family unit. Counselling would have to continue at home.
Second example. A child from a poor social background was admitted with porr weight gain. The parents were illiterate. A previous child had also had poor weight gain, and it had been decided this was due to lack of mothercraft, and not a physical cause - the child had also been NAI. The problem in this case was a very aggressive and uncooperative mother.

The opinion of medical and nursing staff was that this child was suffering in the same way as the first child. Possibly it was the mother's inability to cope with children. However, what evolved eventually was that this mother had been told by neighbours that when a child went into hospital with poor weight gain he was automatically taken into care. So this mother was frightened her child would be taken into care when she was doing her best to look after him. By piecing together information from the community, visiting health visitors, G.P., social workers and ward staff it was eventually realised that however hard these people tried, the child would not gain weight. After intensive investigation a diagnosis of cystic fibrosis was made.

From this situation all staff could learn always to listen to the mother, however aggressive or illiterate. Time must be spent talking to the mother. Also, everyone involved with the child - hospital and community - must work together.

Stress in parents could perhaps be relieved by giving them small general tasks, such as wheeling out the child in a pram. Siblings should be allowed to visit so that their grief need not be hidden, and they could see what was happening to their brothers and sisters. Also, if bereavement took place they must be allowed to live it through.

It was emphasised that specialised training for children's care was essential. (The Chairman pointed out here that it had been DHSS policy since at least 1976 to encourage hospitals and maternity hospitals to allow siblings to visit).

Question:
The majority of sick children are cared for at home - some of these will be suffering from malignant diseases or chronic handicap. In order to provide effective and ongoing care for these children and their families, support systems for the primary health care team are all important. Can members of the group discuss ways in which this can be achieved?

There could be a register of people interested in visiting long term and they should have some training. Community Paediatric Nurses were essential.

Communication was vital. Help should come from all areas - ward, community, psychiatrists, clergy. There should not be just a Monday to Friday service - there must be a twenty four hour cover.

There should be a counsellor among the team. Each member of the team should understand the others' roles.

Prevention was emphasised. Also there should be better education on how to manage sick children at home. Children presented at Casualty who were not admitted to hospital should be followed up at home.

The Chairman mentioned support groups made up of parents of other children, especially in relation to chronic handicap.

The final speaker at the conference was Mrs. I. Menzies Lyth, Social Scientist. She first explained the Stanmore experience.

The Department of Health and Social Security funded a four year research project at the Royal National Orthopaedic Hospital at Stanmore. This was an action research project to try to build an improved model of care for small children in long stay hospitals.

The most important single factor in mitigating the immediate distress of the child when admitted to hospital, and in mitigating possible long term damage, was sustaining intact the mother-child relationship.

At Stanmore, it was gradually realised that it was wrong to think of the ward as a children's unit - it was a family unit. The family was collaborating with the hospital in the care of the sick child. This, of course, had many implications for the role of the nurse. The nurse/nursery nurse must not only be a children's nurse. At Stanmore on the family unit there were just nursery nurses and orthopaedic-trained staff nurses. Often the nursery nurse might be minimally involved with the child patient if the mother was able to be in the hospital much of the time. In the long stay situation the mother must have breaks. At Stanmore any relatives or friends could visit the children.

So a crucial aspect of the nurse's role was the support, and usually the training, of the mother (and family). The nurse must not take over from the mother. The mother must remain the authority over her child. The affects of nurses ousting the mother could be very harmful. Mothers very often felt guilty if their children were sick or deformed. If the mother was made to feel inadequate or inefficient by the nurse, she would lose confidence and be able to do less for her child. Mrs. Menzies suspected this happened in hospitals where, although the policy was unrestricted visiting, the mothers were not there because they were made to feel unnecessary. So much of the work of the nurse in this situation might be with adults and not children.

A further important change at Stanmore in perception of the situation was that mothers ceased to be referred to as visitors. The mothers were not visitors, they were there by right, an essential part of the care system of the children. The nurse must be able to acknowledge the prior claims of the mother to her own child in all matters of ordinary child care.

So, for the nurse, the Stanmore team was now prescribing a very difficult role. She must be able to care well for the child when the mother was not there. It was essential for the nurse and child patient to become attached to each other. It was difficult for the nurse to do this and then surrender the child when the mother or other members of the family were there to care for him. She must then support and help the family. This called for considerable discipline and unselfishness from the nurse. The nurse might have to tolerate inadequacies in the mother and know when to advise. Also, the nurse might have to surrender the work she had been trained for and learn new tasks - helping, supporting, and training the child's family. There was little teaching on this in children's nurse training and nursery nurse training. So the nurse became a family care worker in a setting where she and the family were striving for optimal care of the sick child.

At this point in the talk there was discussion about the problem of learners on wards. At the beginning of the Stanmore project there were learners on the family unit but not at the end - just permanent ward staff, nursery nurses and staff nurses. The problem of the student nurse changing from patient to patient had already been mentioned, but Mrs. Menzies pointed out it was much worse for the patient changing from nurse to nurse. Obviously student nurses must get experience in children's nursing. A compromise could perhaps be found between the training needs of the nurses and the needs of the patients for stability in their relationships.

Mrs. Menzies then spoke of case assignment, which the Stanmore team regarded as crucial and which, she said, was possible to carry out. Case assignment was now in operation, and it worked, at Stanmore. It was not there when the project started but developed as the project progressed. The nurse worked forty hours a week and the child's daytime was ninety hours a week. This meant there must be three nurses caring for one child. Duty rotas were worked out where possible so that the assigned nurse would always be there at times of crisis, e.g. admission days, operation days, ward round, post-operative recovery. It was the nurse's responsibility to work with the mother so that one or other would be there as much as possible. There was also a careful system of re-assignment. There was Nurse Number Two, who came in when Nurse Number One (the assigned nurse) was off duty, and there was Nurse Number Three, who came in very occasionally when Nurses One and Two were off duty. But the emphasis was on the relationship with the assigned nurse, and the other two nurses did their best not to interfere with it.

This raised another issue - the size of a children's unit. The one at Stanmore happened to be the right size - it was a twelve bedded cot unit. Three nursery nurses with a staff nurse were enough to staff it. This was the minimum number of nurses who could cover the time span of the child's week, all of whom were well known to the children. So there was not multiple, indiscriminate care taking, which was the worst thing that could happen to a child in hospital and which happened all too easily when there were student nurses.

Since the Stanmore team left, the Sister, who was in charge of the whole ward of which the cot unit was a part, had devised an alternative system for the bigger children, using student nurses. This was not a case assignment system but a small group assignment system. She had divided the ward into two halves, each about the size of the cot unit, each with its own nurses, and the two halves did not interchange. So the children did not have to relate to all the nurses on the ward.

The assigned nurse was not only important to the child: she was extremely important to the family. She took on the main burden of family care. There were dangers that she could become too involved with the family. The mother (or family) unburdened herself to the assigned nurse, and might confide very difficult problems. So it was important that the nurse listened to these problems, sometimes dealing with them herself by advice or action. This was an ongoing process of stress reduction, the nursery nurse taking it with the family. This was an important issue, and would not happen if case assignment was not in operation, as the mother would not know one nurse well enough to confide in. The nursery nurse had to decide when a problem was beyond her skill and had to be handed over, e.g. to a social worker. At Stanmore this was not difficult as the social worker spent most of her working life on the ward. The assigned nurse, who was with the child when his mother was absent, could give her all the details she wanted to know. Case assignment would be invalidated, especially in a long stay situation, if there were transitory student nurses. At least a solid core of permanent staff was important.

Miss Menzies then spoke of support for the caring team, because this work was extremely stressful. It was impossible to be in touch with the distress of the children and parents without becoming distressed oneself. One way of getting support in this situation was by belonging to a strong, integrated, permanent group. The members of the group knew each other well, cared about each other and were all deeply involved in the work. Mrs. Menzies felt it was impossible to sustain such a situation with perhaps nine student nurses coming and going at six or eight weekly intervals. Again she emphasised the need for at least a solid core of permanent staff.

Mrs. Menzies said that at Stanmore they took a thorough look at management so that boundaries were defined. She felt management was rarely talked about at conferences such as this or in nurse training. Boundaries could not be defined once and for all; this was worked at continuously.

The case assignment system was also very carefully managed and worked at all the time. There was also the question of the management of the mothers - as an essential part of the care system they must come under the authority of the ward sister. The mothers must know how to behave in hospital, e.g. the question of quiet and where they could go. There were weekly mothers' groups to discuss such matters.

Mrs. Menzies felt a good management system was one of the most important ways of dealing with stress. There must be group meetings and individual talks with nurses and parents to work through particular instances of trouble. But this must be backed by a good management system. A lot of the rather slipshod management which existed in most wards came into children's wards and very adversely affected mothers, families and patients. This was why at Stanmore the team spent a great deal of time making the management aspects explicit. They had a 'talking culture' - their culture of truth. There were group meetings and individual talks with the nurses. There was a lot of talking about management problems and boundaries - this was worked at and talked about.

The Chairman summed up by saying that the one group which was concerned with the child from conception to adulthood was the parents. The rest of us, whether teachers, social workers or nurses were concerned with incidents, and were 'enablers' to give the parents the skill, insight and courage to do what was best for their children. This might be in a preventive situation in the community or a therapeutic situation in hospital. Basically it was the parents who had the child's best interests continuously at heart. The rest were providing a service and were servants.

When parents asked where they felt they had been let down they made these points. Firstly, they were not given enough information. Secondly, they were not given the opportunity to learn the skills.

The care of the child was multi-disciplinary - not just nurses were involved. Somehow a more unified service for families with children must be introduced, and this should be community based, although the hospital had a crucial role. The families needed continuity. The Professor said that many parents told him how disastrous it was to them when, in 1974, with reorganisation, their health visitor was changed. Somehow we must get back to continuity of care and not let the patient see a different G.P., hospital doctor or nurse every time.

We must reach the Fourth World and get alongside the disadvantaged groups in society. It must be remembered there were more handicaps and more deaths in Social Class Five.

The Chairman concluded by emphasising the importance of fathers as well as mothers.