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Occupational Therapy for Children with Renal Failure

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This paper outlines the treatment of renal failure at the Royal Children's Hospital in Melbourne, and highlights the physical and psychological problems for children undergoing treatment. The occupational therapy programme is presented, and the author focuses on issues surrounding the chronically ill and dying child.

Key words: end stage renal failure, dialysis, grief work.

In 1976 one of the first children to be treated at the Royal Children's Hospital (RCH) in Melbourne with dialysis was referred for occupational therapy. This six year old boy with end-stage renal failure was referred to meet his needs arising from separation from home, activity restriction and recurrent admissions. Occupational therapy was also required to provide an activity programme graded from bed rest to ambulation. Since this referral the numbers have steadily increased and in October 1984 27 children with end-stage renal failure were being treated.

This paper has been written in response to requests from occupational therapists and students for guidance in working with chronically ill and dying children. While it deals specifically with renal failure it could equally be applied to children with other chronic illnesses such as cystic fibrosis, cancer or severe asthma.

Renal failure is a chronic, long-term problem. The prognosis for quality of life may be poor and a small number of children die due to complications of treatment, or a decision made by the parents to cease treatment. Tables 1 and 2 present background information on the condition.

Renal failure is treated by dialysis and transplantation.

Dialysis

Several children at RCH are treated by haemodialysis. In this method the blood from the patient is circulated through a dialyzer and then returned to the patient. Access is through a shunt or fistula, and usually three

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TABLE 1

RENAL FAILURE

Incidence: 1.5 per million population.

Principal causes in children

1. **Reflux**
   A congenital abnormality causing backward flow of urine from the bladder into a ureter.
2. **Medullary cystic disease**
   The medulla (inner part of the kidney) is made up of honeycomb cysts.
3. **Glomerulosclerosis**
   Hardening of the kidneys associated with hypertension and disease of renal arterioles.
4. **Glomerulonephritis**
   Inflammation of capillary loops in the glomeruli of the kidney. Usually secondary to infection.
5. **Hemolytic Uremic syndrome**
   This syndrome is linked to a viral illness and is characterised by acute hemolytic anemia, thrombocytopenia and renal failure.

TABLE 2

SYMPTOMS OF RENAL FAILURE

1. Nausea and vomiting.
2. Irritability.
3. Drowsiness.
4. Loss of concentration.
5. Fatigue.
6. Confusion and anxiety.
7. Peripheral neuropathy — foot drop, tremor.

TABLE 3

EMOTIONAL PROBLEMS IN CHILDREN SUFFERING FROM RENAL FAILURE

1. Dependency and feelings of being overwhelmed by the magnitude of the problems.
2. Fear and uncertainty.
3. Depression.
4. Grieving.

sessions of 3-4 hours are required each week for haemodialysis to be effective.

The remainder of the children are treated by peritoneal dialysis. This form of dialysis uses the principle of osmosis: the passage of substances through a semipermeable membrane which separates two solutions. The solvent moves from a solution of lesser to one of greater concentration. In peritoneal dialysis the peritoneum is used as a semipermeable membrane and access to the peritoneum is through a temporary or permanent catheter inserted into the abdominal wall. One litre of warm sterile solution consisting of chemicals and water is introduced through the catheter. During the "dwell" time of approximately 30 minutes, movement occurs by osmosis through the membrane. After 30 minutes the fluid is drained off taking with it chemicals, fluids and waste products. Using a dialysis machine this process requires three sessions per week of approximately eight hours per session.

An alternative method of dialysis is continuous ambulatory peritoneal dialysis (CAPD) which is a continuous process in which 4-5 packs of fluid are run through the peritoneal membrane and drained off each day.

CAPD has some advantages over other methods of dialysis for children. This method allows greater freedom, as the child is not dependent on a machine and is able to participate in excursions and holidays; it is comparatively inexpensive and easy for parents to learn; and some of the older children are able to manage CAPD independently.

The disadvantages of CAPD include the amount of time required being daunting for children and their parents; infection being a great risk as the catheter in the abdominal wall makes the child prone to peritonitis; and other complications such as blocked catheter, electrolyte imbalance, cardiac failure and hypertension. Treatment also involves blood tests, injections, renal biopsies and dietary restrictions.

The children suffer unpleasant side-effects such as nausea, vomiting, fatigue and lethargy. Growth retardation is a major problem in children and as well as the obvious physical effects, it produces considerable emotional problems, particularly in boys. Table 3 outlines the psychological aspects.

All children in the unit have lived through periods of rage and despair at the constant assault of treatment, and expressed feelings of helplessness at being "controlled" by a machine. Older children and parents talk often about the continual vigilance and enormous energy output required to maintain effective dialysis and strictly aseptic techniques. One 16 year old said, "You just get up and go to work and live through the day without thinking about it too much. I have to concentrate every minute of the day on just staying alive. It's like being permanently on a tightrope without a safety net."

Transplantation offers the best quality of life if the transplant is successful. The transplanted kidney can be from a live related donor or from a cadaver, better results being obtained from living donors.

The process of transplantation causes considerable stress for the child and his family and particularly prominent are feelings of excitement, hope, guilt, anger. Parents may become overprotective and develop an "emotional hold" over the child. Problems of this nature are particularly noticeable if a parent has donated a kidney. Transplantation of a cadaver kidney also involves marked stress reactions. Some children have been on the waiting list for a long period and become angry and depressed, particularly if others receive kidneys after a shorter wait. It is sometimes difficult for children to comprehend that the kidney goes to the person for whom it will be the best match. Angry and hostile children sometimes wish that an enemy would die so that a kidney becomes available.

Most children and their families hope desperately for a kidney transplant, but the waiting list is long and even if a suitable kidney is found it may be rejected.

TABLE 4

AIMS OF OCCUPATIONAL THERAPY FOR CHILDREN WITH RENAL FAILURE

1. To provide emotional support and outlets.
2. To provide physical activity and encouragement.
3. To maintain contact with outside world.
4. To assist with school work.
5. To develop hobbies and leisure interests.
6. To provide support for family.
7. To assist understanding of dialysis and dietary restrictions.
8. To work as a member of a team in assuring mutual support for all staff members.

Occupational Therapy for children with Renal failure

Renal failure is a long-term problem involving many hospital admissions. Each child is part of a team of family, doctors, nurses, occupational therapist, social worker and play staff (child care workers or kindergarten teachers) and possibly a chaplain. Table 4 outlines the aims of the occupational therapy programme.

The occupational therapist is able to spend a large amount of time with the child each day and is a constant, caring and supporting figure. She also has the enormous advantage of not being associated with painful treatments and diagnostic tests. For the child and his family who are facing the devastating blows of serious illness and possibly death, a long-term relationship with an occupational therapist can be both supportive and growth producing for the child, his family and the therapist.

Renal failure like all chronic diseases is a journey for everyone involved. One of my renal patients aged 10 observed, "It's like we're all holding hands and walking through a forest in the dark".

Working with a child with renal failure can be both frightening and exhausting as it forces the care-givers to confront their own deepest fears about illness and death. It is important to understand that very little children can talk about the gravity of their problems either in plain words or symbolic verbal or non-verbal language. Young children with renal failure often talk about sudden catastrophic ends e.g. car crashes, explosions, fires. They are also interested in strong men, super-heroes and indestructible human beings.

Recurring symbols in speech, art work and choice of games and songs may provide valuable insights into the child's inner world. One eight year old with renal failure was obsessed with flying objects and the freedom and infinity of space. His favourite song included the words:-

"I'm going to live forever,
I'm going to learn how to fly"

Another eight year old's favourite board games were "Headache" and "Trouble".

In a world which at times is frightening and out of control, the children need opportunities to take control and make choices. Children like to draw up a timetable

of activities and choose their own games, craft projects and outings. Close and therapeutic relationships are enhanced by the sharing of feelings of being vulnerable and ideally, a therapist should not feel she has to be omnipotent and all-powerful. Allowing the child to sometimes teach, help and guide the adults caring for him is of enormous mutual benefit.

Communication should be as open and honest as possible and all questions should be answered truthfully and factually. Where appropriate, questions should be referred to a suitable person e.g. doctor, chaplain.

Certainly not all renal patients die but when a child is very sick his family and all the people caring for him should decide what information will be given to him. It is imperative that the child does not feel alone or frightened. He needs to be reassured that everyone is working to help him and he should never be deprived of hope. Ask yourself constantly, "How would I feel if it were me?". Reflect these feelings back to the child with comments like, "I think I'd want to die too" or "You must feel like screaming and swearing!".

Elisabeth Kubler-Ross (1969) has identified the stages of grieving and coming to terms with loss and death: denial, bargaining, anger, depression, resignation and acceptance. It is helpful to be aware of these stages and also to realise that staff members, child and parents may all be in different stages at the same time. They also may move backwards and forwards through the stages and be in more than one stage at once.

A period of yearning and searching for lost abilities and pleasures is often particularly obvious in children and may cause restless, unco-operative and difficult behaviour. This is a painful stage for everyone involved.

Anger is a difficult emotion to handle. The occupational therapist may feel angry with the child, his family, or other staff members, or parents and children may become very angry with the therapist. It is important not to interpret such feelings as a vicious personal attack and to feel demoralized and demeaned. To be surrounded by normal, healthy, independent adults generates tremendous feelings of guilt, anger and loss in children and parents. Staff members feel angry and helpless at being unable to cure the child or to solve insurmountable problems. Talking about angry feelings usually helps to defuse the situation.

Activities in Occupational Therapy

Activities are excellent, but should not be used as props because sitting quietly with a child is too difficult. Activities need to be a balance of:-

1. *Easy, quick reward, short concentration span type activities:*

   games, puzzles, crosswords, mazes, computer games preferably suitable for a child in bed or playing alone.

2. *Long-term hobby interests:*

   Craftwork, art, reading, writing, penfriends, collections, model-making, more complicated games, dolls, puppets, radio, cassettes, television (in moderation). Schoolwork should not be neglected as loss of schooling is one of the major problems in renal failure. Help the child with any work which is sent from school and maintain contact with school friends and teachers by sending letters, drawings and tapes and encouraging visits to the hospital by school friends.

   Writing a book about hospital experiences fosters academic skills and is good therapy.

   One nine year old boy types a book called "I hate to take tablets".

Choice of Activities

Sick children regress in their behaviour and cope best with activities suitable for slightly younger children.

Choose activities which are not too difficult or complicated and ensure success in simple activities before progressing to more complicated tasks. Be cheerful, supportive and encouraging and praise the child's efforts.

Many renal patients are in poor general ill-health or immune-suppressed, so don't use messy or dirty activities e.g. pot plants, sand play, particularly when the child is on dialysis.

If a child is using a dialysis machine select small-sized neat equipment which does not obstruct dialysis equipment. Activities with pieces which can be lost in the bed are frustrating. Basketwork easily becomes entangled with dialysis tubing.

Cooking is an excellent activity. It helps the child to take control and learn new skills and it also enables him to create gifts for the people who always give to him. Cooking sessions for anorexic renal patients usually tempt jaded appetites, but check on dietary restrictions. Salt and chocolate are usually forbidden.

Hospital play is one of the best forms of therapy as it encourages mastery of fears and anxieties and provides an outlet for feelings of aggression and fear. The child is able to verbalize feelings about treatments and procedures and ask questions. Children particularly enjoy dressing up as doctors and nurses and inflicting sadistic treatments on each other. Young children on dialysis like to play with plastic tubing, containers and water and setting up make-believe dialysis. Older children use science textbooks to set up their own experiments in osmosis and dialysis theory. Norman (1982) outlines the use of similar activities at the Royal Alexandria Hospital for Children in Sydney.

Patients often experience lengthy and repeated hospital admissions and become detached from the world outside the hospital. It is important to ensure that the child remains in contact with his normal, daily existence, by talking about what's happening in the world, listening to the radio, watching the news service on television and reading newspapers. Encourage letter and story writing and the making of news and scrapbooks.

Chronically ill children need a life outside the narrow confines of the ward and so-where

wonderful morale boosters. Every child needs exciting events to anticipate and reasons to live rather than just exist.

Emotional Support

Contact with peers and being a member of a meaningful group is part of being human. Renal patients derive enormous satisfaction from friendships formed with each other and patients from other wards. Informal group discussions help the children to verbalise problems and formulate solutions. A relationship with the occupational therapist sustained over many years embodies the concept of "therapeutic use of self". This involves the principle of clear, objective communication within a trusting, consistent and empathetic relationship. Understanding through "active" listening enables the child to ventilate feelings and set his own pace in adapting to his condition.

Chronic illness can foster the development of "sick role" behaviour in even the most robust personality. "Disabled" attitudes and behaviour patterns are very difficult to unlearn. Children need to be encouraged to partake in as many of the normal experiences of childhood as possible. Active daily exercise is encouraged and football and cricket games are enjoyed by all.

Activities of Daily Living

Activities of daily living should not be neglected. Children on CAPD usually need help in fitting tubing into their clothing. Older children like to make their own leather dialysis belts and pouches. Some children need assistance learning to bath, shower and toilet themselves with CAPD catheter and tubing in place.

A minority of children with osteodystrophy (joint deformities due to malabsorption of calcium) have marked bowing of the legs and require help in dressing. Trousers of soft material such as tracksuit pants are easier to manage than jeans. Chronically ill children

The Dying Child

The prognosis for survival of children with end-stage renal failure is improving but a small percentage of children die. The principal causes of death are left ventricular failure and hypertension. Sometimes parents and children choose to cease all treatment, particularly after a number of failed transplants.

Remember that very young children can talk about death either in words or in the symbolic language of their play and drawings. Invariably dying children are aware that adults caring for them are colluding to withhold information. One eight-year old child who had been my friend for many years said, "Everyone is keeping secrets from me. Teach me how to die."

Help the child to complete unfinished business, as however strange the tasks may be he probably has important work to do before he dies. This may involve tours of the hospital or visits to old friends. He also may need to acquire objects, usually of intense symbolic significance. One nine year old girl desperately wanted a "Baby Alive" doll. A ten year old boy acquired a pair of handcuffs and attached himself to the bed rail. Another little girl described very graphically a heaven filled with fun and laughter and wanted a book called "Mr. Galiano's Circus", which she read on the night she died.

Working with a dying child can be devastating and very sad, but it is also an experience rich in living.

A dying child is the best teacher. Try not to be too frightened to get close to him and his family.

When the child dies share your grief with his family, staff members and other children in the ward. The children will need help in coping with their own grief work. They will need help in expressing their sadness, anger and fears and appreciate opportunities to talk about their dead friend. Sick and dying children are not saints and it is important to remember both good and less desirable qualities in the child's personality. Recently the children in the RCH Renal Unit recalled an old friend by saying "Remember how he used to swear? Remember that time he vomited in the nurse's shoes? Remember how we played cricket in the corridor and hit a doctor on the head?"

Working with chronically ill children can be extremely difficult and exhausting. It is also richly rewarding and filled with profound lessons in living. A six year old with renal failure reminded me—"The body is just a box you live in. When you die you leave the box in the ground and go on to a better place. The real magic is being able to see through the box to the person inside."

In conclusion, although no statistical evidence is available it's the general opinion of members of the renal unit team that involvement in an intensive occupational therapy programme enhances the quality of life for children with renal failure and enables them to achieve a greater degree of function whilst giving them a sense of direction and purpose.

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