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EXECUTIVE INDEX

An understanding of loss
and grief in children 1

Meningococcal disease 5

NOTE:

Please check
page 4 for details of a
new professional
development CD Rom.

An understanding of loss and grief in children

Defining and recognising loss

At its most fundamental, loss is the experience of disruption or separation from people, places, animals, possessions, dreams or expectations. For a child a loss may be based on safety, comfort and familiarity, rather than what adults speak of as love or affection. Losses in childhood can be grouped into six categories:

1. Relationship loss (such as through death or separation from people and animals)
2. The loss of an object that gives comfort and connection (a favourite blanket, item of clothing or jewellery)
3. Loss of a secure, familiar environment (changes in family structure or the impact of disasters)
4. Loss of self (ways of being and doing that define us uniquely such as the impact of abuse or physical injury)
5. Loss of skills, abilities and competencies (illness or disability)
6. Loss of familiar habits and routines (changes in daily routine or care arrangements)

Some of these losses are more easily recognised than others, such as:

- the death of a family members or friend;
- being physically or sexually abused;
- the destructive acts of adults (such as acts of terrorism) or nature (such as bushfire) or
- living with alcoholic or abusive parents.

The grief of children however is often disenfranchised (Doka, 2002) and remains silent, unnoticed or forgotten. Frequently, silent losses are related to experiences such as:

- friends or relatives moving away,
- changing teachers,

- being a victim of bullying,
- changes in the health of self or parents, and
- the divorce or separation of parents. The consequences for children of divorce are often more serious than when one parent dies with higher self-blame and ongoing stressors (Clulow, 1990; Worden, 1996).

Children do grieve

Adults often rely on a prevailing myth that children are too young to grieve. When a child experiences a loss they will experience grief, although it may not manifest in the same ways as adults or in ways adults recognize. Evidence however has shown that babies as young as six months manifest early signs of separation anxiety when they find themselves without their primary caregiver for any length of time.

It is hard to describe childhood grief patterns in one single descriptive statement. Grief is not a static process, particularly with children. A number of studies have examined the relationship between cognitive ability, age, developmental sequence, gender, social economic status, cultural and religious factors, social-emotional factors and the type of loss impact upon a child's conception of death (Kenyon, 2001) and how these factors are frequently in a constant state of flux.

There is considerable variability in the acquisition of a child's understanding of death (see Kenyon, 2001). In general terms a child aged between three and five years does not grasp the finality of death (usually equating it either with something like travel or with sleep and ongoing life in some diminished form).

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CENTRE FOR COMMUNITY CHILD HEALTH, ROYAL CHILDREN'S HOSPITAL, MELBOURNE



Very young children clearly have emotionally charged ideas about death and recognise it as a lengthy and possibly permanent state. A child aged between five and nine years tends to grasp that death is final whenever it occurs, but add the claim that death can be avoided in some way (e.g., by outwitting death or hiding from it). At this age death is often conceived as resulting from an external force and often less visible disease processes and deaths, such as from cancer, are seen as confusing to the child. Around the age of nine or ten years of age children grasp that death is final, unavoidable, irreversible and universal.

A child strives to understand their experience of loss from their own frame of reference and often in very concrete terms. In the absence of clear information about illness and death a child will write their own script – often with themselves as the central player. A mother, who was dying of cancer, and her family visited the beach. Her young son repeatedly asked her for an icy-pole. After some time she relented. A number of weeks after her death her young son believed that he had killed his mother. His reasoning was that “I asked mum for an icy-pole. Icy-poles are junk food and are bad for you. If mum hadn’t had that icy-pole she might still be alive today”. These strong feelings of guilt can also give rise to self-blame and confusion.

Children frequently experience an additional difficulty as a consequence of the caregiver’s desires to protect the child from the impact of the loss. This may extend to the child not being permitted to attend a funeral, to see the dying or deceased person or to be present when conversations about the loss take place. This can leave a child feeling confused and emotionally abandoned in the wake of the event.

Our inability to discuss topics of loss and grief openly with children often creates an atmosphere of secrecy, loneliness and isolation far more damaging than the actual death of someone close to them. By helping children put their feelings outside of themselves, either through conversation with caring adults or through their play, we can facilitate their healing. Sharing their feelings can diminish their hurt. It should be noted that some losses impact on the parents and carers so that they become emotionally unavailable to the child as a result of their own experience of grief.

The way children think can affect their capacity to understand the finality, inevitability and irreversibility of death. A young child may see death as a temporary

absence. Describing death euphemistically as “sleep” can further reinforce this misconception and lead to sleeping difficulties in the child. One young child who was told that, “Daddy had an accident and died at work”, thought that his father had soiled his pants and this was what caused him to die. Avoiding euphemisms and using clear and direct language can reduce confusion in the lives of children. As children develop they are able to think about the world in increasingly complex ways and therefore tend to re-grieve their losses over time.

Infants and toddlers react to separations, either temporary or permanent, often by protesting vigorously. This often takes the form of crying, restless searching, heightened anxiety and irritability. The reactions of very young children tend to be bodily ones such as feeding difficulties, bedwetting, constipation and sleeping difficulties. Children don’t grieve consistently. A child tends to mourn in “doses”, on an intermittent basis. Older children can interrupt their sorrow to watch television or play with friends, bewildering adults who wonder if the child really understands and appreciates what has happened. A child may regress and return to behaviour that had been given up prior to the loss, they may become uncooperative, irritable, apathetic or aggressive.

The grief of young children often goes unrecognised because of the child’s tendency to play out their emotional distress and to not communicate their grief in ways that adults readily identify. They may play out the funeral or repeatedly burying dolls or objects in an attempt to master the emotions of grief. Children may also express their emotional distress through drawings, paintings or clay. Conversations about these events allow for the integration and mastery of that experience and the ability of the child to eventually store it in memory.

Responding to loss and grief

It is important that we respond to grieving children. We need to watch for times when they seem to require support and attention. Structure time to spend together, but respect moments when the child chooses to ignore their grief. Children will often look for reassurance from adults about their own safety and that of important people in their lives. Most of all children will need honest, realistic, age appropriate information about the loss event, to be comforted and feel understood. There are many books and videos that can assist children in understanding their experience of loss. Through this

sharing we can give permission for a child to ask questions about their loss and to find some meaning in the experience. We need to allow children to teach us about their grief and to accompany them in their experience of loss. We need to listen carefully to the grieving child. Goldman (2001) provides an extensive listing of specific ideas, techniques, resources and materials to use with grieving children.

Grief is a high-energy activity. It generates a broad range of emotional reactions and can be exhausting. An outlet for this energy of grief can often be found in ritual. Ritual has the capacity to create a safe place with which to engage with the energy of grief and creates a container to hold grief. It is important that we give children choices about their participation in ritual. Lighting a candle, taking flowers, making a drawing, an opportunity to view the body of a loved one and attend a funeral, can be effective ways of facilitating understanding and receiving support.

The question we need to ask is no longer "Do children grieve?" but "When children grieve will they be surrounded and supported by caring adults?"

References

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Author

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Reflection questions:

Please use the following questions to reflect on your current practice as a health promoting nurse in light of this article on grief and loss in children.

1. *Is your professional relationship with parents such that you would feel comfortable raising this topic with them? What barriers might prevent you from doing this and how might they be overcome?*
2. *Do the educational or group activities organised by the centre offer opportunities to introduce this topic? What day-to-day events might present 'teachable moments' to explore these themes?*
3. *Are you familiar with other resources (eg other team members, referral sources, community resources, books, web sites) that could assist you in supporting a grieving family?*
4. *Are there different cultural practices you should be aware of in the groups of parents attending the centre?*

NOTE:

You can email your responses to the "Reflection Questions" for both articles, and/or general comments to:

cpreview.ccch@rch.org.au

or

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Your responses will be placed on the "CPR Notice Board" at www.rch.org.au/ccch/pub

A Professional Development CD Rom

Understanding and responding to the grieving child (1-8 years)

Available in 2003

A professional development program in a CD ROM format is being developed in recognition of the myriad of grief experiences commonly confronted by children of this age including the death of a parent, sibling or grandparent, the separation and divorce of parents, the death of a pet, and the chronic illness or disability of self or parents.

This CD-ROM aims to provide:

- a professional development program based on adult learning principles that challenges the knowledge, skills, attitudes and behaviours of the professionals in dealing with issues of grief and loss
- a theoretical background highlighting the differences/similarities in dealing with grief and loss
- practical strategies to support the child in dealing with grief and loss recognising the different developmental needs of children between the ages of 1-8 years of age
- practical strategies to support the parents of children dealing with grief and loss
- a high quality professional development program that is accessible by the professionals when required
- a flexible model of learning that is suitable for this diverse range of professionals

This CD-ROM will allow staff to learn at their own pace and as the need arises. The benefit of this professional development CD-Rom is that the individual is able to:

- turn to the materials at any time and specifically when needed to support a child and/or family, and
- return to the materials for review and/or clarification of a point.

This program is being developed by the Centre for Community Child Health in partnership with the Centre for Grief Education, with the support of a grant from the "Telematics Trust".

To receive an order form to purchase this CD-Rom, fill in the details below and

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Post to Community Paediatric Review, c/- CCCH, Royal Children's Hospital, Parkville Vic 3052 or

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Topics for 2003

In 2003 Community Paediatric Review will take a "development" focus in each of the following topics:

- Screening and Surveillance – practice implications
- Play and attachment
- Anxiety and self esteem
- School Readiness

Copies of CPR are available from your local Wyeth rep. The publication and back issues can also be printed from the website at www.rch.org.au/ccch/pub

Meningococcal disease

Meningococcal disease is a severe illness causing a number of deaths each year in Australia. Fortunately, although there has been an increase in cases in recent years, meningococcal infection is still a rare disease.

What is the cause?

Meningococcal disease is caused by a bacterium called *Neisseria meningitidis*, also known as the meningococcus. These bacteria can live harmlessly in the back of people's throats, without causing any symptoms. It is only if it gets into the bloodstream that it causes problems.

There are two main types of meningococcus – B and C. These each cause about half the cases in Australia.

What are the symptoms?

Meningococcus causes two main clinical illnesses - meningitis and septicaemia. Sometimes these occur together.

Meningitis occurs when the infection localises to the meninges, which are the layers on the surface of the brain and spinal cord. Most meningitis in children is viral, which is usually not so severe. However there are two main bacteria that cause meningitis in children – the meningococcus and the pneumococcus. Children with bacterial meningitis are usually sicker than those with viral meningitis. Regardless of the cause, the cardinal symptoms of meningitis are fever, headache and neck stiffness. Most patients also have vomiting and are generally very unwell. If the cause is meningococcus, the child may also have a red or purple rash (see below).

Septicaemia occurs when the infection is in the bloodstream. The first symptoms are usually aches in the muscles and joints, a high fever, and often vomiting. Most patients with meningococcal infection develop a characteristic rash. This usually begins as tiny red spots. The important thing to note is that when you press on these spots they don't blanch or go away - they stay on the skin. A good way to test for this is to press a glass against the spots to check whether they go away with pressure. If not, it is critical to get to a doctor or hospital as soon as possible. The spots may then become larger dark purple areas on the skin.

Patients with meningococcal septicaemia can become very sick extremely quickly, over just a few hours. Their capillary beds dilate and leak, causing intravascular

volume depletion with impaired perfusion to all vital organs. This is called septic shock.

What is the treatment?

Meningococcal bacteria can be killed quite easily with penicillin. However the manifestations of the infection, such as septic shock with multiorgan failure, require treatment with large volumes of intravenous fluids and other intensive care support. Many patients require mechanical ventilation. The first couple of days are critical. The mortality from meningococcal septicaemia is about 20%.

What about contacts?

Household contacts and other people who have had close contact in the past week are given antibiotics to ensure they don't also become infected, as they may be carrying the bacteria. Rifampicin is usually used, for two days. This can cause some abdominal upset, as well as orange discoloration of body fluids.

The state health departments are responsible for tracing contacts and giving prophylactic antibiotics, although immediate family members are usually given antibiotics by the hospital. (The child has almost invariably attended a large birthday party or been on a school camp just before becoming ill!)

Who is most at risk?

Children under five years of age, and young people aged between 15 and 25 are at highest risk of getting meningococcal infection, for unknown reasons. It can however affect people of any age.

What can be done to prevent it?

Unfortunately there is no vaccine against the type B meningococcus. The good news however is that three excellent vaccines against the type C have recently become available in Australia. These are called Meningitec (Wyeth), Menjugate (CSL) and Neis-vac-C (Baxter). These are all so-called conjugate vaccines, in which the meningococcal antigen is coupled with a protein carrier so that people of all ages, including infants, mount a good immune response against it. Meningitec and Menjugate use a diphtheria protein conjugate, whereas Neis-vac-C uses a tetanus protein

carrier. All three vaccines seem to be equally effective and safe. It can cause some redness and swelling at the injection site, but no serious reactions have been observed in the tens of thousands of children who have received this vaccine. It is currently recommended to complete the course with the same brand once begun. The conjugate Meningococcal vaccine is recommended for all children over six weeks of age, including adolescents. It is also quite a good idea for adults to have it, though their risk is lower.

It is not yet on the standard immunisation schedule, and is currently quite expensive. It is available from chemists with a doctor's script and from council immunisation services directly (i.e. no script required) and costs about \$70 per dose. Children aged six weeks to six months require three shots, six to twelve months two shots, and those over twelve months need just one shot. Private health insurance extras may cover some of the cost. The dosing schedule is currently being reviewed and there may be further changes in 2003.

Following a detailed evaluation process, the federal government has decided to commit \$40 million/year to provide meningococcal vaccine to those in the highest risk age groups. From 2003 the conjugate meningococcal vaccine will be provided free for infants aged 12 months, as well as for adolescents aged 15 years (in 2003 it will also be provided for adolescents aged 16 and 17 years). During the recent shortage of conjugate meningococcal vaccine some children were given the older polysaccharide meningococcal vaccine (Mencevax-GSK or Menomune-CSL). If children have had the polysaccharide vaccine they are not considered adequately covered and should still have the conjugate vaccine. It is currently recommended that the conjugate vaccine should be given about six months after the polysaccharide vaccine.

Although the conjugate vaccine provides good protection against one strain of the disease it must be remembered that it is still possible for people to get meningococcal infection (type B) even if they have had the immunisation.

Summary

Although meningococcal infection is a frightening thought, remember two things:

1. It is a rare disease.
2. You can reduce your child's risk of getting it by arranging for them to have the conjugate meningococcal vaccine.

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The author would like to thank Jennifer Irwin, Immunisation Coordinator at the Royal Children's Hospital, for providing information to assist in preparing this article.

Reflection questions:

Please use the following questions to reflect on your current practice as a health promoting nurse in light of this article on meningococcal disease.

1. *How do we address parents concern about Meningococcal disease without raising their anxiety?*
2. *This is a very rare disease, how can you use this opportunity to discuss more common but also dangerous disease?*
3. *How do you assist parents to identify whether their baby is ill?*

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