

Communication in the diagnosis of childhood cancer

Delivering bad news is always difficult.

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Delivering bad news is a continuous challenge for medical staff working in paediatric oncology and haematology units and in other areas, such as ICUs. Conveying the news in a thoughtful, caring and hopeful way shows respect and empathy for the family. Effective, compassionate and open communication has a positive impact on the way in which the family copes. It also helps to establish a relationship of long-term trust. Communicating the diagnosis should be the first building block in an ongoing communicative process.¹ An honest and a humane approach that conveys some hope is advocated.¹⁻⁵

Preparation

- Arrange a time that suits both parents/parent with life partner, and/or family members. Meet both parents if possible.^{2,5}
- Provide a quiet, private and comfortable setting with sufficient seating.¹
- Set aside enough time for parents to ask questions and express their emotions.^{1,2}
- Minimise interruptions. Consider having a 'please do not disturb' notice outside the room.^{1,2}
- Provide a competent interpreter, if necessary. Inform him/her of the seriousness of the conversation. Be sensitive to and respect different cultural and religious views.¹
- Sit next to the parents as a partner in the communication process rather than behind a desk. If the child is present, encourage the parents to touch and hold their child.¹
- Communicate in easy and understandable layman's terms. Avoid medical jargon and technical language, but explain appropriate terms where indicated, e.g. bone marrow aspiration, trephine biopsy, MRI, PET scan.

Conversation

Ensure that communication is a two-way conversation during which the family is in control. Pause frequently and enquire whether they understand the diagnosis. Allow time for questions. It is important to listen to the family and respond to their emotional and practical needs.^{2,4,5}

Start by asking the family what they understand about their child's illness. This will indicate what we, as doctors, need to tell them. It

will also indicate whether they have considered the diagnosis of cancer and if there are any misconceptions.²

Communicating the diagnosis should be the first building block in a continuously communicative process.

If the patient is a young child, the doctor should explain the diagnosis, procedures, treatment and possible side-effects in terms that are appropriate for his/her age in the presence of the parents. In this way the medical team will know what has been said to the child, and the parent's burden will be lighter. A separate discussion is usually advised, unless parents request otherwise. Open communication helps to build a relationship of trust with the child and the family so that they know what to expect on the new journey.^{1,2,4}

Protective parents sometimes prefer that the diagnosis is not disclosed to their child. One should advise parents that the unknown is often more distressing to the child than the known. The child is surrounded by other children who have symptoms and signs of cancer and its treatment, such as alopecia. Such children are therefore aware that there is something seriously wrong with them.² Teenagers should preferably be present when the diagnosis is disclosed, unless their intellectual ability is limited. It builds trust and enables them to actively take part in the treatment.²

The family must be informed that it is very difficult to plan their lives while the patient is on treatment. Ask them to discuss any other information, e.g. internet, supplements, etc., with the medical team. There are three important aspects for parents to remember, i.e. diagnosis, treatment and aetiology.²

Diagnosis

When giving a diagnosis, use a term that the family can understand, e.g. cancer of the blood (they may not understand 'tumour' or 'leukemia'). Ask if they know someone who has cancer, and anticipate their association with possible loss. The presenting symptoms play an important role, e.g. a diagnosis of cancer of the brain in an ill-looking patient with neurological symptoms is easier to understand than lymphoma in a well-looking patient with a lump. The diagnosis often brings certainty after a period

of uncertainty. Convey to the parents if there are diagnostic problems and try to understand their possible frustration. When the family receives the diagnosis it is the beginning of their journey with the disease. Explain the site of origin and pattern of spreading of the disease, and what is known about the patient in this regard. Before starting treatment obtain written consent from them and agreement from the patient where indicated.²

Treatment

Establish a plan. In most paediatric cancers the goal is curative treatment. If the goal of treatment is palliative, it should be conveyed to the family as part of the management plan.² Psychosocial support from a social worker, child psychologist and parent support group should be started. Explain chemotherapy and/or radiotherapy, surgery when indicated, duration of treatment, possible side-effects, and the route by which chemotherapy will be administered. Everyone on treatment will experience some, but not necessarily the same, side-effects.

Ensure that communication is a two-way conversation during which the family has control.

Aetiology

There are very few well-known causes of childhood cancer. Families and children often blame themselves for the diagnosis. One must reassure them that nothing that they did or failed to do led to the diagnosis. If there was a delayed diagnosis, acknowledge it. Inform the family that doctors understand that it is a very difficult time for them. They are not expected to

remember all the information given. They feel more comfortable if they are assured of follow-up conversations. The family should remember the following: the doctor knows the diagnosis, he/she has a treatment plan, and nobody can be blamed for the illness.²

The family must be informed that it is very difficult to plan their lives while the patient is on treatment.

Prognosis

Compassionate doctors often avoid giving a prognosis or present it in over-optimistic terms to try to protect the family from pain and suffering. However, although distressing, parents want the information because it assists them in current and future decision making.⁶ Prognosis or risk should be explained verbally ('probably', 'possibly') and numerically in percentages or ratios.¹

Follow-up meetings

The often distressed and anxious state of the parents at diagnosis influences their ability to hear, understand and accept all aspects related to it. It is therefore useful to provide them with written, printed and audiovisual material if available. Follow-up meetings are also of great value to discuss information already given again and to address questions.

A compassionate doctor in a therapeutic relationship is often a meaningful pillar of strength for distressed parents and comforts the child during this challenging journey of childhood cancer.

References

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In a nutshell

- Use a quiet and comfortable private room. Minimise interruptions.
- The conversation should be compassionate and caring. Convey hope and reassure the family of support.
- Set aside enough time for the family to express emotions and ask questions.
- Use a competent interpreter if required.
- Avoid using medical jargon. Give accurate information. Communicate clearly.
- Teenagers are usually present at the initial conversation.
- A young child is usually not present when the doctor meets with the parents.
- There should be an honest indication of the prognosis.
- Hear and retain: diagnosis, treatment, goal of treatment, aetiology.
- Review the discussion, and give printed and audiovisual material.