The adolescent with cancer: Psychological and ethical issues
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Adolescence can be one of the most difficult times to receive a diagnosis of cancer. These patients are typically diagnosed later than paediatric or adult cancer patients, and their care often falls into a gap between adult and children's services. Adolescence is also a time of rapid physical, psychological and social change as children become young adults. Cancer and its treatment may critically interrupt this process, at a time when young people do not have the personal resources to cope alone. In this talk I will try to highlight the important psychological issues that all health professionals should be aware of when dealing with adolescent patients, and the ethical dilemmas that these can lead to.

Adolescents are striving to gain independence from their parents and families yet the diagnosis of cancer can shatter their emerging sense of autonomy, making them reliant again on their families for support and help with difficult decisions. Adolescent cancer patients may also have to deal with issues beyond their years such as future fertility and ultimately the possibility of death, and they will need great support and understanding in this process. Their image and status in the eyes of their peer group is increasingly important, and hair loss, implanted lines, and changes in body image can damage their self-confidence in social and sexual relations. Time away from school can also isolate young people from their friends and may jeopardise educational achievements. The adolescent’s ability to cope with these challenges will depend on their age and maturity, but also on family support and the clinical environment where they are treated.

Adolescents may have reduced adherence and cooperation with treatment due to failure of trust and communication with clinical teams. They may have anger about their diagnosis, or different beliefs about their illness and treatment. They may have specific requests as to how their care is conducted which must be respected, but also combined with the need for safe and effective care. Adolescents often suffer from significant depression and anxiety during cancer treatment. The signs that typically indicate this in younger children may not be present, yet they may feel less confident than adults to express this. Counselling, psychological therapy, medication and perioperative anxiety management techniques may all be useful.

Important ethical tensions can arise between a clinical team’s duty to provide care for their patient, against the increasing imperative to respect the views and decision making rights of young adults. Respect for autonomy is a key principal in ethics, and allowing young people to make decisions also fosters their development and growing autonomy. There are clinical benefits too from fully involving young people in decisions about their care. Trust and engagement are likely to be increased, and active participation in therapy can be enhanced.

The principal of truth telling arises from respecting a patient’s autonomy, but truth telling in oncology is complex, and often difficult. Adolescent patients may already be well informed about their condition via the internet or the experiences of fellow patients, although these sources are not always reliable. They may therefore have their own beliefs about treatment, which can be difficult at times for clinicians to reconcile. Adolescent patients should be given as much information as they request or need so that their decisions are as autonomous as possible, and their decisions continue to make sense to them in hindsight.

Allowing young people to make decisions over healthcare is also a contentious area in law, but courts are increasingly prepared to support the wishes of adolescent patients, while the UN Convention on the Rights of the Child also makes explicit in Article 12 that young people have a right to be heard and have their views taken into account. Judging the extent to which young people are able to decide about their treatment can be difficult at times. In English law young people over 16yrs of age may give consent by themselves for treatment or investigation, whereas for younger adolescents the principals of Gillick competence would need to apply. Making medical decisions requires understanding of health, disease and how the body works. Difficult concepts such as causation, uncertainty, and balancing risk against future gain must also be mastered. By 14 yrs. of age, most adolescents have these cognitive skills given, but autonomy and decision making ability can regress during illness, and stress.

The situation where a young person refuses important or lifesaving treatment is most difficult of all. For anaesthetists, many procedures such as lumbar puncture, and bone marrow aspiration and vascular access procedures often require general anaesthesia and we may be called upon to resolve
a refusal of treatment. In English law parental consent is deemed sufficient up to a young person’s 18th birthday, although in some circumstances, courts will support a younger patient to override their parents’ wishes. Ethically however the issue is more complicated. Parents have the right to make decisions about their children’s upbringing and care, although these rights must diminish as their children mature. Overriding the wishes of a competent young person could be practically very difficult, and would be unlikely to promote their long term cooperation. However there may be real concern that a young person could bitterly regret a refusal if it leads to lasting harm, or losing the chance of cure. Ethically we are duty bound to explore why a young person is refusing care, and whether their refusal is a manifestation of a deeper underlying problem, such as a family conflict. This approach may lead to successful help for their troubles, and better engagement with cancer treatment.

Some situations may lead to concerns over child protection issues which must always be discussed with a child protection lead, or other official figure. At this point an adolescent’s confidentiality may need to be compromised if they divulge information that you are duty bound to report. Ideally the full involvement of a young person’s family should be helpful in solving conflicts, although there will be times when they do not wish this. Children’s advocacy service may provide an alternative source of support for an adolescent, but some disputes may need to be resolved in court. This process may feel a drastic last recourse, but it can also act as a neutral second opinion, providing protection both legal and moral for clinicians who must either override a young person’s wishes, or accede to an unwise decision.

Adolescents may also need to participate in decisions about limits to treatment and end of life care, and these discussions can be intensely difficult to hold. Some patients may already have DNAR orders in place when presenting for anaesthesia for palliative procedures. These orders are intended to prevent futile attempts at resuscitation from disturbing the natural process of dying, but may be inappropriate in the context of anaesthesia. Here the physiological instability may be unrelated to their underlying condition, and the procedures of anaesthesia may overlap with resuscitation techniques. Outcomes from resuscitation in theatre are usually much better than other settings, and anaesthesia may not even have been anticipated when the DNAR decision was drawn up. A recent survey indicated that most paediatric anaesthetists would request that a DNAR order is suspended or altered for the perioperative period. Appropriate modifications can be based on the procedures a patient would accept, or alternatively focussed on their ultimate goals when limiting treatment.

Outcomes from cancer treatment continue to improve, and the prospects for many adolescent patients will be good. However the burden of ‘survivorship’ may include chronic health conditions, problems with fertility and fear of recurrence for the rest of their lives. Organisations as the Teenage Cancer Trust in the UK have driven a move for the provision of adolescent cancer care to be given increasingly by specialist units. These can create an environment where adolescent patients feel less alone, and provide the necessary expertise and support including psychological counselling and family therapy. Anaesthetists should also be able to draw on these resources when encountering difficult issues. Further guidance can be found in the relevant GMC publications, and advice should always be available from medical defence organisations or Trust legal advisors.

The Teenage Cancer Trust  http://www.teenagecancertrust.org/

References


