

these SIOP guidelines. One would hope to see the ideas for “best practice” for the follow-up of long-term survivors taking their place in the context of standards like these.

Gibson and Soanes focused on the situation in the UK, and defined the nursing qualifications required viewing a degree as an essential starting point. This may be realistic there, but is definitely not so in other countries. For example in South Africa, which has a mixture of First and Third World elements, we have only a limited nurse training programme in adult oncology, and nothing for paediatric oncology. Many other countries are in an even worse state than ours. It seems to be generally accepted that only 20% of the world’s children receive effective treatment for their cancers, yet most

children with cancer are in developing countries and receive virtually no treatment. Within this context, there has to be a balance of resources devoted to the different aspects of total care for the patient and the family. However, having “standards of care” does set down targets that everyone can aim for.

In summary, Gibson and Soanes successfully highlight the need to have a greater support and follow-up for long-term survivors, and suggest ways in which the nursing profession could play a major role. One would, however, like to see this as part of a holistic approach to identify and document the good practices and standards of care that should be aimed for by the entire team that cares for the child with cancer, and which can be adapted to meet local requirements in different parts of the world.

Commentary

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In The Netherlands, approximately 70% of the 400 children, aged 0 to 15 years, who are diagnosed each year with cancer survive. This percentage, although depending on the type and stage of the tumour, has steadily increased over the last two decades. As we know, quantity of life is very important, but recently it seems to be that quality of life has become more important. To improve quality of life, we need to know the disease that has been diagnosed, the treatment given and how the whole experience was perceived from a physical, psychological, social as well as spiritual aspect—and what the problems are in the long-term. To discover if the quality of life can be improved, long-term follow-up for children with cancer is necessary to provide answers to all these questions.

There are no differences in the follow-up strategies of the United Kingdom and The Netherlands. In The Netherlands, we have five Paediatric Oncology centres, and they all have a long-term follow-up programme. However, each centre has its own protocol. In all five of the Paediatric Oncology centres, the children/young persons consult a paediatric haematologist/oncologist. The role of the other disciplines involved in long-term follow-up, however, is not clear and differs for each centre. The nurse does not have her own part in the

long-term follow-up procedure in The Netherlands. With the exception of one Nurse Practitioner student at the Beatrix Children’s Hospital, University Hospital, Groningen, nurses in The Netherlands do not have an independent consulting hour for children with cancer during treatment. Many nurses assist the paediatric haematologist/oncologist, and give some advice, but it is not formally organised. I have for three years, as a clinical nurse specialising in paediatric oncology, given an independent consulting hour for children with cancer during treatment. The questions posed in this session usually refer to the problems and needs parents and children experience in their daily life. More evidence-based nursing in relation to how children and parents survive the diagnosis of childhood cancer, the treatment and what is going on during the long-term follow-up is of major importance to increase quality of life.

As Gibson and Soanes mentioned in their article, it is very important to know if all children need long-term follow-up and, if they do, who is the best person to provide that care and in what setting?

Evidence-based medicine will be necessary to provide an answer to the first part of this question. The information which is already available for the long-term follow-up of all childhood cancer survivors can be used as evidence to decide if a child needs a long-term follow-up for physical problems or not. Perhaps the best way to determine if a child needs a long-term follow-up because

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of psychological, social and/or spiritual problems would be to ask the child/young person themselves and/or their parents, as they will know if there are problems and/or needs. Continuity of care [1] is therefore important and needs to be provided by a multidisciplinary team in which one paediatric haematologist/oncologist is responsible for one child during diagnosis, treatment and long-term follow-up. Continuity of care also reassures children/young persons and their parents.

Regarding who is the best person to provide care, everybody knows that a nurse is more accessible than a physician. Whether it is a clinical nurse specialist, a nurse practitioner or a consultant nurse does not matter, but each centre will have to decide which of the three types of specialist nurse will be suitable for their population of patients and also appropriate for their organisation and culture. This is not only applicable in the Dutch Paediatric Oncology centres, but perhaps also to centres in the United Kingdom.

In the Dutch setting, the nurse must be in a Paediatric Oncology centre. They should be skilled in communicating with children/young persons, with parents and with all the other health care professionals in hospitals and in community care that are involved in the care of children with cancer.

Finally, it is important that articles like the Update from Gibson and Soanes are written, as they hopefully will bring together health professionals in discussions with one another and with the patients and parents. In this way, everybody's contribution to the long-term follow-up of childhood cancer patients and, in particular, the contribution of nurses may be maximised.

References

1. Hockenberry-Eaton MJ. *Essentials of Pediatric Oncology Nursing*, 1998.