CCLG RESEARCH PROJECT UPDATE

Identifying the support needed by children with sarcoma

Project title: Development of a paediatric version of the Sarcoma Assessment Measure (SAM-Paeds): a specific tool for assessing quality of life in children with sarcoma

Lead researcher: Dr Madeleine Adams, Children's Hospital for Wales

Project Stage: Complete (December 2022)

Funded by: CCLG and Team Jake, Angus's Door and The Jenni Clarke Fund

ABOUT THE PROJECT

Currently, very little is known about quality of life during treatment for sarcoma in childhood, and it is very important when designing treatment strategies that these issues are understood. This is particularly important because the upcoming international clinical trial for rhabdomyosarcoma (the FaR-RMS trial) will measure quality of life between the different treatment options to identify differences.

The research team at Children's Hospital for Wales, led by Dr Madeleine Adams, aims to develop a questionnaire that can measure of quality of life for children undergoing treatment for sarcoma. The Sarcoma Assessment Measure: Paediatric Version (SAM-Paeds) will be developed as an addition to a similar tool for adults.

Once developed, SAM-Paeds will be used in the Far-RMS study to better understand quality of life for patients during treatment, and whether there is any difference in quality of life pre- and post-operative radiotherapy.

The researchers will develop this in four stages:

1. Meeting with patients and parents to find out the specific quality of life issues that occur during treatment and using these discussions to create the initial questionnaire
2. Fine-tuning the questions to make sure they are important and not repetitive
3. Formatting the questionnaire and using specialist techniques to ensure questions are understood as intended
4. Testing whether the questionnaire measures what it intends to

Patients, parents, and healthcare professionals looking after children with sarcoma will be involved in all stages of questionnaire and is a parent member of the study group who has been involved in the initial study design. The final version will be used in clinic appointments as well as research studies to identify areas where patients require support.

RESULTS

The project has identified that sarcoma has a number of effects on the quality of life of children, young people and their parents. The researchers hope that their SAM-Paeds questionnaire can be used alongside generic measures to improve quality of life assessments within clinical trials. This would help doctors understand more about potential new treatments and how they affect patients.

The SAM-Paeds tool is possibly the first sarcoma-specific quality of life measure for children and young people. This is important because there is concern that the generic measures currently used in clinical trials are not sensitive enough to the specific issues that affect children and young people with sarcoma. The tool can and will be used both in clinical trials to investigate how different treatments affect children with sarcoma, and also in the clinic to flag up patients who need access to support.

Development of this tool has led to more use of the quality of life assessment within the FAR-RMS clinical trial for rhabdomyosarcoma, and other international clinical trials are keen to use it too.

WHAT'S NEXT?

The SAM-Paeds tool will be entered into the FAR-RMS clinical trial for rhabdomyosarcoma to form part of the quality of life assessment. Discussions are also underway for to use the tool in the ICONIC trial for osteosarcoma and for Ewing's sarcoma trials.

The researchers hope that the inclusion of SAM-Paeds will make the quality of life assessments within the trial more relevant to sarcoma patients, which will help inform treatment and care decisions going forward.

Team Jake

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Children's Cancer and Leukaemia Group

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