Whole-Body MRI for cancer surveillance in Ataxia Telangiectasia: A qualitative study of the perspectives of people affected by A-T and their families

Renata Neves[1], Blanca De Dios Perez[1], Tierney Tindall[1], Natasha Schneider Fernandez[2], Rafal Panek[3], Sophie Wilne[3], Mohnish Suri[3], William Whitehouse[1], Sumit Jagani[3], madhumita dandapani[4], Robert Dineen[1], and Cris Glazebrook[5]

[1]University of Nottingham School of Medicine
[2]Independent Patient and Parent Representative
[3]Nottingham University Hospitals NHS Trust
[4]University of Nottingham Children's Brain Tumour Research Centre
[5]Institute of Mental Health University of Nottingham Nottingham United Kingdom

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Abstract

Background/objectives: Ataxia Telangiectasia (A-T) is a complex inherited disease that is associated with an increased risk of malignancy. Surveillance guidelines have demonstrated significant health benefits in other cancer predisposition syndromes (CPS). Evidence-based guidelines for cancer screening are not currently used in the UK for people affected by A-T. This study aims to understand how people with A-T and their parents feel about cancer surveillance using whole-body MRI to inform the future development of cancer surveillance guidelines. *Design/Methods:* We conducted semi-structured interviews of people affected by A-T. Data were analysed inductively using thematic analysis. *Results:* Nine parents of children with A-T and four adults with A-T were interviewed. Five main themes emerged from the data. All participants viewed cancer screening for children with A-T as invaluable and emphasised the perceived value of early detection. The second theme acknowledged the anxiety associated with cancer and cancer surveillance and the third theme highlighted the perceived limitations around current practice, with the responsibility for monitoring falling too strongly on parents and patients. The fourth theme identified the need for effective preparation for cancer screening, including clear communication, and the challenges of MRI screening were recognised in the fifth theme with specific recommendations made for improving the child's experience. *Conclusion:* This study suggests that stakeholders are positive about the perceived advantages of a cancer screening programme. Ongoing support and preparation techniques should be adopted to maximise adherence and minimise adverse psychosocial outcomes.

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