

COMMENT

## **Malignant Melanoma: How Do We Meet the Needs of Young People and Their Families?**

Wendy McInally

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Malignant Melanoma: How Do We Meet the Needs of Young People and Their Families?

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## Malignant Melanoma: How Do We Meet the Needs of Young People and Their Families?

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Malignant melanoma is a type of skin cancer that affects around 132,000 people across the globe every year (World Health Organization, 2017). If diagnosed early, prognosis is good. Yet, despite improvements in treatment that have driven improved survival, due to a combination of factors such as lack of awareness, light skin color, blonde or red hair, number of moles, family history, and excess exposure to ultraviolet (UV) radiation, particularly in childhood, incidence of malignant melanoma continues to increase in some countries. Although malignant melanoma is more often diagnosed in older people, it increasingly affects adolescents and young adults (AYAs). In the United Kingdom (UK) for example, it is the fifth most common cancer in AYAs (Cancer Research UK, 2017; Information Services Department [ISD], 2017), and in Scotland, of the 180 young people between the ages 15 to 24 years diagnosed with cancer every year, on average 14 will be diagnosed with malignant melanoma.

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In particular young females than males are at risk from the disease. A study by Kyle et al. (2014) highlights the importance of awareness of skin cancer risk associated with UV exposure and encouraging sun protective practices. Such awareness and the establishment of protective health-related behaviors may have potential to reduce the burden of malignant melanoma in adolescents and early adulthood, as well as in later life. Malignant melanoma is an important disease within this age group and awareness of prevention and UV exposure is essential, as are early diagnosis and care management within age appropriate specialist services (Murray & Edgar, 2012).

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Curative treatment is dependent on early diagnosis and the stage of the disease at diagnosis. The treatment for malignant melanoma varies depending on the stage of the disease. For all cases, treatment is usually surgical followed by immunotherapy which may be used as an additional treatment for high risk patients, (Cancer Research UK, 2017). Clinical trials using immunotherapy are currently taking place, but optimal timing for this type of intervention has not been determined. Systemic treatment is used in

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palliative and end of life care along with radiotherapy, especially for patients with metastatic disease. However, the recognition of early symptoms, in order that prompt diagnosis and treatment is available throughout the cancer pathway, is crucial (Zebrack, Kent, Keegan, Kato, & Smith, 2014). 40

## Understanding and meeting the needs

In Scotland, the *Cancer Plan for Children and Young People* aims to ensure that children and young people aged between 0 to 25 years diagnosed with cancer have equal access to the best possible care and treatment as early as possible. The Managed Service Network (MSN) for Children and Young People with Cancer has been charged with delivering this vision (The Scottish Government, 2016). It is important that, as young people mature into adulthood, early diagnosis and defined care pathways are established. These pathways should consider the individual age, cancer type, and the future risks of late effects from treatment as well as the personal needs of the young person and their family. 45 50

Caring for young people with cancer requires a range of specific knowledge, skills, and experience to deliver often complex care regimes both within the hospital or community environment (Gibson & Soanes, 2008). A teenager or young person typically begins their cancer pathway within children's services, teenage cancer units, or adult services. In the UK they are given a choice of where they would prefer to be treated if they are between the ages of 19 to 24 years (National Institute for Health and Clinical Excellence [NICE], 2005). 55 60

A diagnosis of cancer can often occur at a time when the adolescent or young person is in the process of developing their early adult life plans and are at a major crossroads in their life (McInally, 2013). The diagnosis and subsequent treatment at this juncture may impact significantly on their life plans and their ability to fulfil their full potential. A diagnosis of cancer at this time may add to the stressors associated with a normal transition from young person to adulthood. It may also impact on their relationships, quality of life, and psychological wellbeing, among other components of their lives. The needs of the family cannot be separated from those of the individual with the disease, but both would value information and support offered in a structured way. Implications for practice suggest that young people wish to be empowered to take care of themselves. 65 70

Care delivery by competent health professionals who are knowledgeable about the immediate and long term implications of treatment is a fundamental requirement in order that young people and their families can be supported and prepared for what lies ahead. Services need to ensure clearly defined pathways are developed for the care of AYAs with malignant melanoma and review the effectiveness of these pathways on a regular basis. 75

However, there is a tendency to view the ideal treatment and care experience as arising out of specialist services that are age appropriate although this is not readily available for all AYAs with cancer across the globe due to different health care systems and resources (Carr, Whiteson, Edwards, & Morgan, 2013). This means that there is a need to ask what actually happens in practice from their own perspective and what information is given about services for ongoing care and support.

**Next steps for research and practice**

Existing literature reveals that there is no national or international research that focuses on the experiences of AYAs living with malignant melanoma. This can also be said for the experiences the families share with the adolescent or young person endeavoring to cope with the disease. Previous research has tended to focus on the experiences of young people living with other types of cancer such as leukaemia and lymphoma rather than malignant melanoma (Murray & Edga, 2012). Thus, while models of young people’s cancer experience have been developed (Taylor, Pearce, Gibson, Fern, & Whelan, 2013) it is not known whether these hold true for those diagnosed with malignant melanoma. Anecdotal evidence suggests that adolescents and young adults living with malignant melanoma may be experiencing fragmented services and insufficient support, potentially leading to poorer outcomes. Only by focusing on the experiences of young people living with malignant melanoma will services be designed that meet the needs of these young people and their families. The increasing incidence of the disease in Scotland and elsewhere makes this an even more important pursuit.

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