PIONEERING NUTRITION SERVICES FOR sickle cell disease

Claudine Matthews, dietitian and trailblazer, is pioneering the development of nutrition services for sickle cell disease in the UK.

As dietitians we are in a unique and fortunate position as qualified health professionals to treat the diet and nutrition problems of individuals as well as addressing issues at a wider public health level. We can help achieve the health-related aspirations of our patients as we are highly skilled to assess, diagnose and treat nutritional problems using leadership skills and evidence-based practice. However, nutrition remains largely underused and under-recognised as a management tool for sickle cell disease (SCD) patients amongst dietitians, as well as within the wider SCD community.

PATHOPHYSIOLOGY EXPLAINED
SCD is a unique and often debilitating genetic long-term condition (LTC). Its main pathophysiological features – namely increased red cell turnover (haemolysis) resulting in a chronic anaemia and vaso-occlusion (blockage of small and large blood vessels with sickle shaped red blood cells) resulting in infarction and tissue damage – has pertinent nutritional implications. This contributes to the undernutrition observed in many SCD patients. Undernutrition is deemed to be a critical feature of this chronic LTC and nutrition should ideally be a part of the normal clinical management of the condition.
As nutrition and diet experts, dietitians stand to make a tremendous difference in improving the nutritional management and overall dietetic outcomes for this specific patient population. This is an area largely under-developed and untapped, evident in the gross lack of sickle cell-specific nutritional guidelines, standards of care and resources, as well as low levels of involvement of dietitians in managing the nutritional needs of this patient population.

**THE IMPORTANCE OF NUTRITION ACKNOWLEDGED**

At the 9th Annual Sickle Cell and Thalassemia Advanced conference, a global event, the acceptance of two abstracts for a poster competition, the first ever from a dietitian, proved to be major breakthrough in recognising nutrition’s role in this field. This conference brings together all the leading researchers, specialists and health professionals from around the world including the US, Brazil, Italy, Africa and many others to discuss the latest developments in research and management of SCD and thalassemia.

One of the posters titled *Nutritional Assessment of Sickle Cell Disease: four main components to consider* was judged as one of the two winning posters of the conference. This winning poster featured the main content of a recent article which emphasises the four main components to be considered when assessing the nutritional risk of the SCD patients.

The significance of the winning poster was evident from the level of interest demonstrated by the attending delegates and the number of requests received to provide presentations highlighting the importance of nutrition as a management option in SCD. Informal discussions and networking with local and international sickle cell consultants proved to provide further evidence of the importance of changing the mind-sets and practice to include nutrition as a viable management tool in SCD patients.

**POOR REFERRAL RATES OF SCD PATIENTS IS A CHALLENGE**

Furthermore, the conference provided an opportunity to debate and challenge some of the findings of a national dietitians’ survey, conducted by myself, to explore the involvement, knowledge and attitudes of dietitians in relation to SCD in the UK. An American haematologist questioned why only 20% of dietitians thought having an SCD interest group was a good idea and a factor to increase dietitians’ involvement. This enquiry drew attention to a more pertinent point related to low referral rates of SCD patients by sickle cell consultants, doctors and nurses for dietetic input. The survey indicated that 84% of responding dietitians agreed that low referral rates of SCD patients for dietetic input impacted their involvement in managing these patients. Clearly there is a dual responsibility to achieve increased dietetic involvement by dietitians and SCD teams, to refer patients for dietetic input.

**A TIME FOR CHANGE**

Change however takes time and ingrained organisational and individual cultures require persistent awareness and perseverance to allow for people to assess the benefits. It is my hope that the thought of making a difference in the life of a vulnerable SCD patient would eventually win over the barriers and limitations of lack of involvement and swing the pendulum in favour of change.

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On a positive note, the waves of change are turning in favour of the development of nutrition services for SCD amongst the wider SCD community. A second major breakthrough came when I received an invitation to contribute to the review of the *Standards for the Care of Adults with Sickle Cell Disease in the UK*, to lead on the development of nutrition/dietetic standards of care. The history surrounding the importance of including nutrition as a bona fide management option for SCD will be forever changed, as for the first time ever nutrition will be acknowledged and included in these national clinical standards.

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**REFERENCES**

4. Sickle Cell Society. Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK.