

**Developing a model of best practice
for people with Cutaneous T cell lymphoma (CTCL) and
their caregivers:
an investigation of multidimensional supportive and palliative care
needs**

Final Report to Dimbleby Cancer Care

A collaboration between St. John's Institute of Dermatology, the clinical Palliative Care service at Guy's and St. Thomas' Hospital and the Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, King's College London

Funded by Dimbleby Cancer Care



Executive summary:

1. Cutaneous T cell lymphoma (CTCL) is a rare condition which can progress slowly but in some cases progresses rapidly with significant, sometimes distressing symptoms. There is a paucity of evidence regarding patients', informal unpaid carers' and health professionals' experiences of CTCL. This is the first study to investigate all their needs and propose an evidence-based response. The following recommendations are generated from the evidence.

2. There is no universally accepted tool for measuring physical, psychosocial or spiritual outcomes in CTCL, which means that routine assessment of needs is often not undertaken and comparison of outcomes across studies is difficult.

Recommendation:

- Agree a multidimensional tool for routine assessment of needs which is acceptable for comparing outcomes of clinical trials.

3. Delay in diagnosis is common and a significant concern to patients and carers. This is due to its rarity as a disease, lack of education and training amongst general practitioners and dermatologists and some difficulty in making a histopathological diagnosis.

Recommendations:

- Raising awareness of early signs and symptoms of CTCL which might cause concern amongst general dermatologists through sources of information (e.g. website) or education might be helpful.
- Provide information for patients and carers regarding why diagnosis can be difficult.

4. Clarity and honesty in information giving was extremely important. Information about the diagnosis and treatments was not always conveyed well.

Recommendations:

- Communication skills training is needed for all clinicians involved in CTCL care.
- Ensuring recommended regional referral pathways (for example, Improving outcomes for people with skin tumours (update)). National

Institute for Clinical Excellence. May 2010) are known and processes are clear in order to facilitate clear communication between health professionals regarding what information patients have been given.

5. The impact of the condition on all aspects of life may be significant. Currently there are too few sources of information easily available to patients and carers, either on websites or in other forms.

Recommendations:

- Patient assessment should include physical, psychosocial and spiritual outcomes, including impact on finances (laundry, travel, and employment). Resources could be collated via a patient/clinician website which could be patient led and hosted by an appropriate charitable organization.
- A range of support services for patients and their carers should be offered and available at the treatment centres and locally where possible. (Examples of services that are said to be helpful include contact with a Clinical Nurse Specialist, face to face support groups, on line support groups).

6. Functional multidisciplinary meetings exist in many areas however communication between healthcare professionals is an area in need of improvement. Patients and carers described problems in continuity of care which contributed to their burden.

Recommendations:

- A clear referral pathway, with good internal and external relationships to facilitate patient diagnosis and treatment appropriate to their current need.
- A functional multidisciplinary meeting attended by key members from dermatology and oncology , with representatives of extended services (hematology/pathology/psychology/palliative care) present as part of planned regional/supreregional networks to plan the resources needed for treatment both within and outside of the local area.

7. Caring for patients with CTCL with significant symptoms over a prolonged period of time can be psychologically and physically demanding for health care professionals.

Recommendation:

- Ensure adequate organizational, educational and psychological support are available and offered to health care and allied health care professionals, particularly ensuring that those who spend prolonged

periods of time in close contact with people with CTCL are assessed and supported.

8. Bereavement support is an important part of care.

Recommendation:

- Letters to patients' bereaved relative from their key consultant should be considered standard practice.
- The key worker should make contact with the bereaved primary carer after death to establish needs for follow up.

9. Regional and supraregional CTCL services range in their stages of development, with some services in existence for significantly longer than others.

Recommendation:

Development of the UK Cutaneous Lymphoma Group of service providers to encourage data collection and pooling, enable sharing of information regarding patient-related concerns, organizational developments based on shared best practice, co-ordinated research including clinical trials to guide service development and ensure nationally agreed standards are implemented.

10. A summary of this work was presented at the UK Cutaneous Lymphoma Group meeting in Leicester 16th May 2013 and the recommendations approved by the group following review.

Project steering group

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Centres invited to participate in service interviews

Birmingham
Bristol
Cardiff
Edinburgh
Leeds
Lanarkshire
Liverpool
Manchester
Newcastle
Nottingham
St. Johns Institute
Southampton

Acknowledgements:

We gratefully acknowledge the opportunity given by Dimbleby Cancer Care to explore the needs of this extraordinary group of patients and their families, and the health professionals who willingly gave of their time and expertise to enable us to undertake this study.

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