Assessing quality of life with ePROMs in cutaneous lymphoma patients

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Introduction and Aims

Cutaneous lymphoma (CL) can cause many distressing symptoms for patient which can lead to a negative impact on their quality of life (QoL).



Plaque stage mycosis fungoides

Materials and Methods

- The Christie launched the ePROMs programme in December 2018, and for those with CL it was launched in Dec 2020.
- ePROMs were sent out to 138 patients between 8th of January and 25th of March 2021.
- Evaluation of the ePROMs programme ran from April 2020 to June 2021.
- Both patients and clinicians were asked questions to try and determine their opinion on ePROMs.
- Patients were asked the following (see table):

How useful overall would you say the ePROMs

questionnaire is, where 0 is not useful at all and 6 is the

Similarly those who were receiving treatment had worse impacts to their QoL than those under surveillance

(see figure below).

The difference in average symptom score for each theme on ePROMs questionnaires between patients on surveillance and/or topical therapies and those on active treatment



surveillance and/or topicals

As expected, ePROMs questionnaires received some

Reference: DermNet NZ.

- Dynamic assessment of QoL is important in evaluating therapeutic interventions and determining a therapeutic strategy for our patients.
- ePROMs (electronic patient reported outcome) measures) are electronic standardised questionnaires that are sent out to patients in an attempt to gain an understanding of their symptoms, mental health and QoL with the hope of ultimately improving patient care.
- The PROMS questionnaire was developed based on Skindex 26 and the EQ 50 assessment tools.
- A link to the questionnaire is sent to the patient's mobile phone, or via email if requested, on the day of their first appointment and subsequently 5 days prior to any upcoming reviews.
- See the figure below for an example of how ePROMs appears on a patient's device.

Content

Instructions:





most useful it could be?

Do you think your answers to the form are addressed in

consultations with your doctor?

Does filling in the form have any effect on your mental

health and wellbeing, whether this is positive or negative?

Results

- The response rate was 76%, therefore it is feasible.
- •31% of patients responses showed that their disease was significantly impacting upon their QoL i.e. they scored a total of $\geq 50/100$ OR scored 6 across 5/15 domains OR scored \geq 3 across 10/15 domains.
- When comparisons were made between those with early and advanced stage disease, it was found that those with advanced disease suffered more in terms of their QoL (see figure below).

The difference in average symptom score for each statement on ePROMs questionnaires between patients with early stage cutaneous lymphoma and advanced stage

negative comments, but on the whole opinions from patients and clinicians were positive (see figure below).



Conclusion

- As expected, there are some areas of the questionnaire that received criticism therefore it is crucial to alter such areas and endeavour to improve the questionnaire in order to advance this service.
- In the future, the ePROMs

The first set of questions ask about your symptoms from your skin





questionnaire could be utilised to improve the management of various diseases by monitoring disease progression and its effects on the patients QoL.

This service could also aid with evaluating the efficacy of advanced different treatments in a variety of patients.

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• Our aim was to assess the feasibility of ePROMs and evaluate it through a series of interviews with patients and clincicians as an innovative method of monitoring the QoL of patients with CL.