

Reviewing the feasibility of Chronic GVHD patients completing FACT BMT quality of life forms in Photopheresis Unit NP057

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INTRODUCTION

FACT-BMT is a 47-item, valid and reliable measure of five dimensions of quality of life (QoL) in bone marrow transplant patients.

The form is divided into 5 different aspects

- Physical,
- Social/family,
- Emotional,
- Functional
- Additional concerns.

The 2015 National Institute of Health (NIH) consensus paper, recommended using FACT BMT in the assessment of QoL in chronic Graft Versus Host Disease (cGVHD) patient, and so the Photopheresis unit commenced using the form in April 2015.

The FACT BMT version 4 questionnaire was given to each patient every 3 months and the results were recorded.

In October 2016 completion of the form was reviewed.

The form has 50 questions in total, however only 37 questions are currently used in scoring.

AIMS AND OBJECTIVES

The aim of this review was to ascertain the feasibility and compliance rate on completing the Fact BMT QOL form.

For the purpose of this review the unit looked at the compliance of completing 100% of the form not whether the form was valid for scoring.

Method

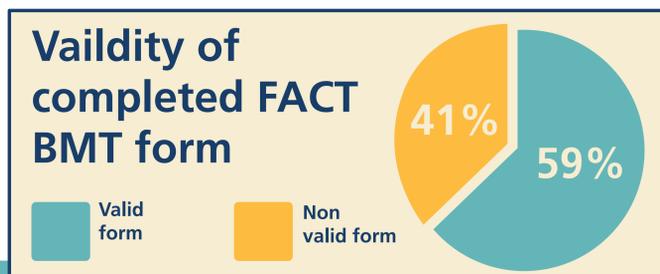
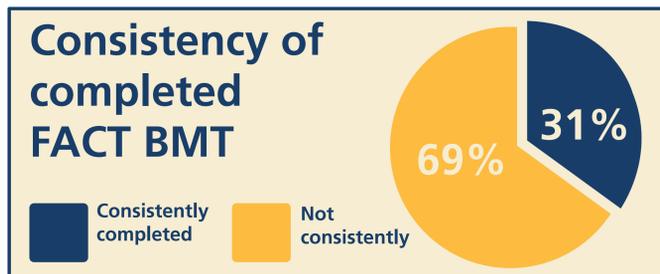
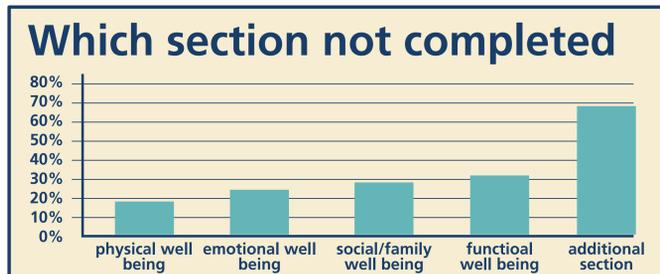
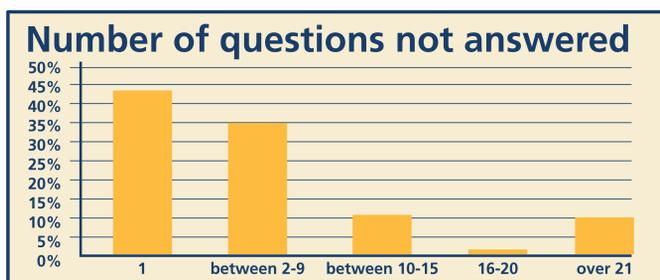
FACT BMT score was recorded for each patient on a local data-base.

The review of the FACT BMT form included:

- Proportion of patients that had completed all the form.
- The number of forms not completed.
- The number of questions not answered.
- The areas not completed.

Acknowledgements.

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Results

- Over the 18 month period 59 patients attended the Photopheresis unit.
- 217 forms were filed in the patients notes.
- 63% (n=137) forms had been fully completed with all 47 questions answered.
- 37% (n=80) forms were not fully completed.
- The question in the social/family well-being section relating to intimate relations, if the box 'prefer not to answer' was ticked, this was regarded as completed.

Forms that were not completed:

- 43% (n=34) had only a single question not answered.
- 35% (n=28) did not answer between 2 and 9 questions.
- 11% (n=9) did not answer between 10 and 15 questions.
- 1% (n=1) did not answer between 16 and 20 questions.
- 10% (n=8) did not answer over 21 questions.

Of the forms that were incomplete,

- 59% (n=47) only one of the 5 sections was not completed.
- 41% (n=33) had more than one section which was not completed.

The breakdown of sections not completed was as follows.

- 18% (n=15) did not fully complete physical well being section.
- 29% (n=23) did not fully complete social/family well being section.
- 24% (n=19) did not fully complete emotional well being section.
- 33% (n=26) did not fully complete functional well being section.
- 69% (n=55) did not fully complete the additional concerns section.

Reviewing the data collected over the 18 months showed 69% (n=41) did not consistently complete all the form.

In addition to reviewing the compliance, the unit also reviewed how many forms had a valid score.

For the form to have a valid score, the form needed to be completed 80% and each given section needed to be 50% complete.

- 59% (n=35) of patients had a valid score on every visit.
- 41% (n=24) of patients did not have a valid score on every visit.

Conclusion

Whilst FACT BMT has been identified within the NIH guidance as an effective tool in the review of QoL in patients with cGVHD, the review has highlighted concerns in patient compliance.

As missing data will result in an inaccurate record of quality of life, staff should actively encourage patients to fully complete the form allowing the collected data to be analysed and evaluated.

It shows that patients may find it difficult to complete the form due to its length and finding some questions irrelevant to their life.

Following this review the unit plans to use the FACT BMT data to ascertain what impact Photopheresis has on patients quality of life and compare the findings with the Lee score, which is also currently in use in the unit.