

Patients' experiences using Patient Reported Outcome Measures in basic palliative care

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BACKGROUND

The need for improvement of basic palliative care for people suffering other life-threatening diseases than cancer has gained considerable focus in Denmark. Patient Reported Outcome Measures (PROM) may be used to identify patients' palliative care needs. A new PROM containing EORTC QLQ-C15-PAL combined with new items related to lung, heart, and kidney diseases, family, spirituality, intimacy etc. was developed by The Danish Health Data Authority.

The aim was to evaluate patients' experiences with the new PROM in basic palliative care among people with life-threatening cancer, lung, heart, and kidney diseases.

STUDY DESIGN

A feasibility study was conducted from November 2021 to October 2022 at 11 sites (Danish hospitals, municipalities and general practices). To evaluate the feasibility of the new PROM, patients completing PROM during their usual care were asked to complete an evaluation survey. A sub-sample of patients also participated in a semi-structured interview regarding their experience with PROM.

DATA

270 patients answered the evaluation survey. Seventeen semi-structured interviews were conducted with patients.

COMMON EXPERIENCES DERIVED FROM THE INTERVIEWS

Screening for palliative needs

- PROM can lead to increased awareness about the development of the illness.

Dialogue support

- PROM initiates a conversation about the things that lie behind the answers.

Improved treatment

- PROM is important because the patients get a follow up on their PROM answers.

ANALYSES

Quantitative data were analysed descriptively. Qualitative data were analysed thematically into three themes:

- 1) Experiences of completing the PROM
- 2) Relevance of PROM content
- 3) PROM as a dialogue support tool.

RESULTS

Preliminary analyses show that 84 % found the PROM easy to complete, 87 % found the items relevant, and 71 % answered that completing the PROM was useful in preparation for dialogue with healthcare professionals.

Interview findings suggest that the patients attached great value to the new questions about family, spirituality and intimacy. However, data also indicate that if the PROM was not used in the dialogue, patients experienced it as a burden.

CONCLUSION

The study suggests that a majority of patients find the new PROM beneficial, and that supplementing the EORTC QLQ-C15-PAL with items regarding family, spirituality and intimacy add important value. However, the perceived value of PROM seems strongly linked to active use of the responses in a dialogue with the healthcare professionals.

REFERENCE: A Danish report has been published at the PRO Secretary at the The Danish Health Data Authority in 2022 [Evaluering af pilotafprøvning af PRO til basal palliation – Rapport udarbejdet for PRO-sekretariatet, Sundhedsdatastyrelsen].

