



Symptoms and health-related quality of life in patients with advanced cancer - A population-based study in Greenland



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ARTICLE INFO

Article history:

Received 4 January 2017

Received in revised form

14 March 2017

Accepted 17 March 2017

Keywords:

EORTC QLQ-C30

Advanced cancer

Quality of life

Greenlandic

Translation

ABSTRACT

Purpose: The aims were to describe symptoms and health-related quality of life (HRQoL) in Greenlandic patients with advanced cancer and to assess the applicability and internal consistency of the Greenlandic version of the EORTC-QLQ-C30 core version 3.0.

Methods: A Greenlandic version of the EORTC QLQ-C30 v.3.0 was developed. The translation process included independent forward translation, reconciliation and independent back translation by native Greenlandic-speaking translators who were fluent in English. After pilot testing, a population-based cross-sectional study of patients with advanced cancer receiving palliative treatment was conducted. Internal consistency was examined by calculating Cronbach's alpha coefficients for five function scales and three symptom scales.

Results: Of the 58 patients who participated in the study, 47% had reduced social functioning, 36% had reduced physical and role functioning and 19% had reduced emotional and cognitive functioning. Furthermore, 48% reported fatigue, and 33% reported financial problems. The Greenlandic version of the EORTC had good applicability in the assessment of symptoms and quality of life. Acceptable Cronbach's alpha coefficients (above 0.70) were observed for the physical, role and social functioning scales, the fatigue scale and the global health status scale.

Conclusions: Patients with undergoing palliative treatment in Greenland for advanced cancer reported high levels of social and financial problems and reduced physical functioning. This indicates a potential for improving palliative care service and increasing the focus on symptom management. The Greenlandic version of the EORTC-QLQ-C30 represents an applicable and reliable tool to describe symptoms and health-related quality of life among Greenlandic patients with advanced cancer.

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1. Introduction

Indigenous people in the Arctic region have increasing incidence of cancer, and their risk of developing lung or colorectal cancer is higher than the world average (Kue Young et al., 2016). Cancer incidence in Greenland in 2012 was 164, with a rate of 289 per 100,000 inhabitants. A journal audit conducted in Greenland revealed that patients were typically diagnosed late in the disease

trajectory (Ministry of Health, 2011). Cancer is thus the most common cause of death in Greenland with 105 deaths in 2012 (Landslægeembedet Grønland, 2013). Epidemiological studies of the prevalence of cancer among Greenlanders show that lung cancer is the most common, followed by gastrointestinal cancer and breast cancer (Gelvan et al., 2015; Jensen et al., 2010; Kirkegaard, 2012; Kue Young et al., 2016; Nielsen et al., 2004).

Greenland is a part of the Danish Realm, and health care services are provided in close collaboration with Danish hospitals. In 2004 chemotherapy for breast, lung, pancreatic and gastrointestinal cancer was transferred from Denmark to Greenland, and can now be given at Queen Ingrid's Hospital (QIH) in Nuuk, in collaboration

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with oncologists at Rigshospitalet (Gelvan et al., 2015). A systematic review of the organization of palliative care for rural populations demonstrated a pronounced lack of well-organized services as well as problems with adequate symptom control (Evans et al., 2003). These findings are likely to be applicable in Greenland as palliative care services are scarce and face substantial infrastructural and geographical challenges (Gelvan et al., 2015; Departementet for Sundhed, 2013). Cancer patients in Greenland usually have to travel long distances away from their relatives, which can affect their quality of life. Palliative care patients and their families in rural and remote areas can have a range of unmet needs including access to services, information about illness, practical help, and medical support (White et al., 2011). Although 84% of participants in the Greenlandic public health survey was satisfied with the access, treatment, communication and the use of interpreters in the Greenlandic health care system (Dahl-Petersen and Bjerregaard, 2016), many patients with advanced cancer have unmet needs that increase throughout the disease trajectory.

A useful starting point for launching and promoting palliative cancer care in Greenland is a systematic assessment of a representative sample of Greenlandic patients with advanced cancer. Structured use of assessment tools aims at providing symptom relief, but can also enhance research, education and public awareness in palliative care (Strömngren et al., 2002). Attention to specific factors that can have a major impact on treatment outcome would help to focus and structure palliative care services. Appropriate and systematic assessment of patients with multiple symptoms requires a multidimensional evaluation of their symptoms, clinical and psychosocial characteristics, and health-related quality of life (HRQoL). The burden of symptoms and HRQoL in Greenlandic patients with advanced cancer have not yet been studied, and no instrument to assess quality of life has been developed or translated.

The aims of the current study were to describe symptoms and HRQoL in Greenlandic patients with advanced cancer and to assess the applicability and internal consistency of the Greenlandic version of EORTC-QLQ-C30 core version 3.0.

2. Methods

After pilot-testing, a cross-sectional study was undertaken in a population of patients with advanced cancer in Greenland from June 2015 to March 2016. Data collection was primarily through structured telephone interviews, supplemented with face-to-face interviews as necessary.

2.1. Translation procedure

Greenlandic is an Inuit language and has similarities with native languages spoken by indigenous people in Canada and Northern Alaska. A Greenlandic version of the questionnaire was developed according to the translation manual of the European Organization for Research and Treatment of Cancer (EORTC) Group (Dewolf et al., 2009). For forward translation, the English version of the questionnaire was independently translated into two Greenlandic versions by native Greenlandic-speaking professional translators who were also fluent in English. The first author compared the two Greenlandic versions and discussed them with a group of colleagues with knowledge of English but Greenlandic as their mother tongue. A reconciled Greenlandic version was created. For back translation, this reconciled version was independently translated into English by two professional translators who were strong in both English and Greenlandic.

The first author compared the two English versions, and revisions were made in discussions with the same group of

colleagues. This resulted in an interim Greenlandic version.

2.2. Pilot testing

The interim Greenlandic version was pilot-tested in Nuuk among 10 patients with advanced cancer in treatment at the oncological outpatient clinic at QIH. Face-to-face interviews were conducted with patients who were 18 years old or above, came from different villages and settlements in Greenland, had Greenlandic as mother tongue, and were able to give informed consent. Any perceived difficulties with completing the interview were registered. The translation process ended with external proof-reading of the final version (see appendix 1) by a professional Greenlandic translator provided by the EORTC group.

2.3. Setting

Greenland is the world's largest island with a total area of over 2 million km². About 80% of the island is covered by permanent ice and the population of about 56,000 people lives along the coast. The majority of the population is Inuit and only 10% were born outside of Greenland (Statistics Greenland, 2016). The health care system is organized in five health care regions, with QIH in Nuuk functioning as the central hospital. Chemotherapy is given in an outpatient clinic in the department of internal medicine and follows Danish guidelines (Gelvan et al., 2015). Patients from other villages and settlements arrive for treatment by helicopter, boat, plane or ship. Health care services including medication, hospital treatment and transportation to hospitals are free for permanent inhabitants in Greenland. Some patients may receive oncological treatment at a Danish hospital after assessment and referral from a physician.

2.4. Recruitment, inclusion and exclusion criteria

We used the electronic medical record (EMR) to identify Greenlandic patients in treatment for cancer in Greenland or Denmark during the period September 2014 to March 2016. Inclusion criteria were age >18 year's old, advanced cancer with ICD codes DC00-DD48 and with no curative or antineoplastic treatment options. The patients must also be willing to participate and permanently resident in Greenland. If patients spoke Danish the validated Danish version were used. Exclusion criteria were cognitive impairment, inability to understand the study information, or treatment that was intended to be curative.

The eligible patients were contacted and given information about the purpose of the study. They were enrolled in the study after providing informed consent.

2.5. Demographic data and variables

Data collection followed the dataset of the European Associations for Palliative Care (Sigurdardottir et al., 2014). The questionnaire thus enquired about sociodemographic data i.e. living situation, gender, number of children, education, employment, income, place of residence and language. Clinical information about diagnosis, planned treatment, place of treatment, and use of analgesics was extracted from the electronic medical record. Data were stored in the internet-based data system REDCap (Harris et al., 2009).

Patients were categorized as either Nuuk residents (if their permanent address was registered as Nuuk) or non-Nuuk residents, and as having lung cancer or non-lung cancer according to the electronic medical record. Although no official definition of poverty exists in Greenland (Christina Schnohr et al., 2007), patients with

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