ACTA ONCOLOGICA
2020, VOL. 59, NO. 10, 1139–1144
https://doi.org/10.1080/0284186X.2020.1762927

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ORIGINAL ARTICLE

Patients' perspective in the context of proton beam therapy: summary of a Nordic workshop

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ABSTRACT

Introduction: On 15–16 November 2019, the Skandion Clinic in Sweden hosted the first Nordic workshop on 'Patients' perspective in proton beam therapy'. The workshop was conducted to describe and compare the patient care in PBT clinics in the Nordic countries and to initiate a collaboration, with the target to ensure patient participation and reduce the risk of inequity of access by lowering the barriers for accepting PBT in a distant clinic. The overarching aim of this workshop was to describe and compare the use of patients' perspectives in the Nordic PBT clinics.

Material and Methods: Twelve participants attended the workshop, representing Denmark, Norway and Sweden. The participants were registered nurses working in patient care, researchers, physicist and leaders of the Skandion Clinic.

Results: The consensus of the workshop was that systematic use of patient experiences on individual and group level is essential for developing clinical practice and understanding the overall effects of PBT. A difference in how the Nordic countries use patient experiences in clinical practise was found. The importance of lowering the barriers for participation in national proton trials and proton treatment were emphasized, however, there is a lack of knowledge about individual and organizational barriers to accepting PBT, and further research is therefore needed.

Conclusion: Collaboration between the Nordic countries regarding patients' perspectives in the context of PBT is of importance to compare national differences as well as to find similarities, but most importantly to learn from each other and to improve patient care. Nordic collaboration with focus on systematic collection of patient-reported outcomes in the context of PBT is unique. Collaboration in research offers the possibility to increase the inclusion of patients' perspectives in study protocols.

ARTICLE HISTORY
Received 10 January 2020
Accepted 23 April 2020

Introduction

A growing interest in proton beam therapy (PBT) for treatment of cancer has arisen in the world as well as in the Nordic countries. Due to the physical properties of protons, the treatment has the potential to limit unwanted radiation in normal tissue surrounding the target volume [1]. There is evidence for favorable health-related quality of life (HRQoL) and reduced toxicity with PBT compared to conventional radiotherapy (CRT) for some cancer diagnoses, for example, brain tumors [2], head–neck cancers [3] and lung cancer [4].

Use of protons for cancer treatment was suggested as early as in 1945 [5], and treatments started in the late 1950s in Sweden, and USA. In September 2019, 83 centers worldwide (27 in Europe) were treating patients, and 39 additional centers are under construction, of which 10 are in Europe (www.ptcog.ch). The cost of delivering proton therapy is higher than for CRT, and the availability of the treatment is limited [6,7].

PBT in the Nordic countries is represented by the Danish Center for Particle Therapy (DCPT) in Denmark and the Skandion Clinic in Sweden. Both clinics are designed to treat approximately 1000 patients yearly. Norway is opening a PBT clinic in 2024.

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Patients' perspective

Patient and public involvement

Patient and public involvement (PPI) is regarded as central to increase the relevance of healthcare research and improve healthcare quality. PPI has been defined as to 'promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels' [8].

Patients' values, experiences and perspectives on scientific evidence and clinical expertise can be used at an direct care level and at an organizational level for improving quality of care [9]. PPI is suggested to increase healthcare quality and equity, since PPI can give voice to marginalized or underserved patient populations, ensuring that all needs are expressed and met [10]. PPI is international recognized [11,12]. In the UK, the multidisciplinary Clinical and Radiotherapy Translational group has a strong tradition of PPI in research, aiming to maximize quantity and quality of life for patients receiving radiotherapy [13].

The purpose of the Swedish Patients Act [14] is to strengthen the patient's position and to promote patients' integrity, self-determination and participation in health-care. The Swedish Regional Cancer Centers (RCC) were establish as a strategically important part of the National cancer strategy, with advisory councils including patients and next-of-kin representatives [15].

Denmark established The Danish Knowledge Center for User Involvemnet in Health Care in 2011 with the aim of developing a knowledge base for the involvement of patients and their relatives in the Danish health care [16]. Denmark has no national guidelines regarding PPI, but patient involvement is well described in regional guidelines [17].

Patient-reported outcomes

Patient-reported outcomes (PRO) are an important means to involve patients in direct care and as a basis for improving quality. PRO has been defined as 'any report coming directly from subjects without interpretation of the physician or others about how they function overall or feel in relation to a condition and its therapy' [18]. PRO can be captured through self-reports or through interviews [18]. Patient-reported outcome measures (PROM) can measure diverse outcomes, such as HRQoL; physical, social and mental function; and generic or specific cancer symptoms. Inclusion of PRO assessments is salient in oncology, due to the sequelae of cancer, its treatments and associated psychosocial factors affecting the patient's subjective experience and functioning [19]. PRO adds value to clinical practice due to increased patient involvement and person-centered communication [20]. In essence, a PROM enables investigators to address a decision-relevant question, for example, whether a new therapy delivers significant clinical benefit from the patient's perspective.

Studies based on PRO data from patients treated for brain tumors PBT have been published by the Proton Care Study Group (PCSG) [21–24]. Other PRO studies involving PBT have been conducted on mostly prostate cancer and single studies on breast, brain, head/neck and lung cancer [25].

Logistic in PBT

Since the development of PBT facilities demands large investments by the national healthcare systems, it is important to optimize the use of the facilities by treating a vast majority of the patients who may benefit from PBT. However, access to PBT in the Nordic countries implies for patients to be treated far away from home, requiring daily transportation or accommodation in a hotel. A potential risk of inequity cannot be excluded since some patients may have personal or practical barriers to receive a long course of treatment in a national centralized clinic. It is of great importance to get a better understanding of the patient perspective regarding centralized treatment in a distant clinic, and on this basis, tailor an intervention to reduce the inconvenience of being away from home.

The aim of the workshop

On 15–16 November 2019 the Skandion Clinic in Uppsala, Sweden, hosted the first Nordic workshop on 'Patients' perspective in proton beam therapy'. The workshop was conducted to initiate a collaboration with the target to ensure patient participation in clinical trials and thus access to PBT and reduce the risk of inequity of access by lowering the barriers for accepting PBT in a distant clinic. The aim of this study was to describe and compare the use of patients' perspectives in the Nordic PBT clinics. The workshop discussed following clinical issues and future collaboration in research:

- How can we optimize the systemic use of patient experiences to develop clinical practice?
- How can we involve patients in daily care, symptom management and cancer rehabilitation?
- How can we increase patients' possibilities to receive PBT?

Method

Participants

Twelve participants attended the workshop representing Denmark, Norway and Sweden.

Two radiotherapists/registered nurses, the leading study nurse and a clinical nurse specialist formed the DCPT group. The group emphasize the DCPT's aim to integrate development and research into clinical practice.

One physicists represented the proton group in Norway, mainly as an observer.

The Skandion Clinic was represented by one clinician (the chief executive officer) and two registered nurses (one head of the department). Four registered nurses, three with Ph.D. degree and one doctoral student represented the PCSG. The PCSG was established as a result of a commission from the

Skandion management to form a research group conducting caring research in conjunction with PBT. The research group is not part of the treatment staff or located in the clinic.

Results

The Nordic countries are in different stages in developing patient perspective in their daily practice. Denmark is developing strategies for person centered care, with focus on the patient experiences, parallel to the clinical development of the new clinic and future research project. Sweden is developing the clinical practise as a result of PRO measurements. Norway is in an early stage with a planned opening a PBT clinic in year 2024.

How can we optimize the systemic use of patient experiences to develop clinical practice?

Denmark

After a panel discussion with patients treated at the DCPT and healthcare professionals, patients' needs for implementation of PRO in clinical practice were identified. The patients emphasized the importance of individualized consultations targeted to each person's needs.

The current strategy in Denmark recognizes that involvement of the patient perspective has fundamental clinical value, and PRO is therefore a part of clinical practice. The purpose of using PROs is to support patient centered communication. International PBT PRO are not yet developed, thus clinicians identified 17 brain specific items from European Organization for Research and Treatment of Cancer library. Furthermore, the questionnaire contains 2 write-in-boxes for the patient to report other symptoms and issues to discuss with a health care professional. Ten patients were involved to ensure the relevance of the questions.

Prior the development of the DCPT;s website, 14 patients treated with protons abroad were interviewed in order to target the patient information to issues most relevant for patients receiving proton treatment. Likewise, 20 interviews with patients were performed at the end of the course of treatment with protons, to evaluate activities and procedures in the clinic and thereby identify possible barriers to patient satisfaction.

Sweden

Before receiving the first patient, the Skandion clinic gave lectures to contact nurses around the country to help create a well-informed supportive network around the patient

The current Swedish strategy of the ProtonCare project is to collect PRO from all adult patients at the start of PBT and continue until 60 months after completion of the treatment. The overall aim is to determine whether PBT is superior, in terms of patient-reported outcomes and patients' experiences, compared to modern CRT in a short- and long-term perspective. Patient-reported, treatment-related toxicity is collected on a daily basis during the treatment, with the newly developed Radiotherapy Symptom Assessment Scale (RSAS) (submitted manuscript). Anxiety and depression are evaluated with the Hospital Anxiety and Depression Scale (HAD) [26], insomnia with the 7-item Insomnia Severity index (ISI) [27], fatigue with the Multidimensional Fatigue Inventory (MFI-20) [28] and HRQoL with EORTC scales [29,30].

Data are collected before start of the treatment, during treatment, at end of treatment and 1, 3, 6, 9, 12, 24, 36 and 60 months post treatment to capture any variation in early and late symptom burden. Qualitative interviews during and after treatment are conducted to capture patients' expectations and experience of participation in decision-making, continuity, symptoms and healthcare needs as well as the experience of living away from home in a context without their regular social network to support them.

Data are continuously analyzed and published by the PCSG [21–24]. National meetings are held annually with healthcare staff from Skandion and coordinators from referring radiotherapy centers. The purpose of the meetings is to discuss implementation of the results in the clinic as well as quality assurance of the inclusion procedure. Results from the studies have been used to develop the care at the clinic.

How can we involve patients in daily care, symptom management and cancer rehabilitation?

Denmark

In Denmark the patients report their symptom burden and well-being on a tablet weekly. The responses are available in the patient medical report and used to support the dialogue between patient and clinician. In addition, PROs are collected by telephone 14 and 28 days after treatment, by a nurse from the DCPT. The aim is to ensure the patient's sense of security and comfort in the period between treatment completion and first contact at the local department.

During implementation of PRO at the DCPT, an interdisciplinary group supports patients and colleagues in the use of the web-based PRO tool. This group also defined the purposes for the use of PRO and described the PRO workflow in clinical practice. In addition, support from management is essential during implementation of PRO. The results will detect acute side effects of proton treatment, which is useful in the further development of clinical care.

DCPT has close collaboration with physio- and ergotherapists, and a room is designed for different types of training. At the end of the course of treatment, all patients complete a questionnaire which is followed by a scheduled conversation with the contact nurse regarding further needs for rehabilitation.

Sweden

Based on the results of the PCSG, the nurses in the Skandion Clinic have implemented a consultation meeting regarding symptom control, including the patient, nurse and physician. approximately 2–3 weeks after the start of treatment, at the time when symptoms normally occur. The nursing group in the clinic develop the clinical care to meet the needs reported in the PCSG studies. Based on the study results, the patient information and the website have been improved with information on side effects and self-care advice. An activity group has been started to plan for rehabilitation activities and to include more rehabilitation professions such as physiotherapists. The effects of these implementations will be evaluated.

How can we increase patients' possibilities to receive PBT?

Denmark

DCPT is a national centralized treatment facility treating patients from the five Danish regions. To investigate the problems of receiving treatment in a distant clinic in Denmark, a questionnaire has been developed concerning transportation, accommodation, family situation, finances and practicalities. The patients are invited to complete the questionnaire at the first visit and at the end of treatment. In addition, interviews with patients will be conducted to explore the patients' needs and perspectives further in relation to planning of the stay and the daily life during the course of treatment.

A future research project at the DCPT is planned to identify barriers affecting clinical trial participation and use of proton beam therapy among Danish patients with head and neck cancer. Awareness of barriers will lead to development of interventions to support patients during the decision-making process regarding participation in national proton trials and proton treatment. The aim is to develop an intervention to minimize the risk of inequity in the access to proton therapy in Denmark for patients with head and neck cancer. Furthermore, differences between participants and non-participants in proton trials will be investigated related to socioeconomic and geographical factors, QoL and health literacy. In addition, interviews with patients will be conducted to explore patient needs and perspectives on daily life during the course of treatment.

Sweden

The number of patients treated with PBT are smaller than expected in Sweden. The reasons why the Skandion clinic is underused, are unclear and under investigation. The Skandion clinic strives for health equity, and that patients that benefits the most are treated.

There are different rules and regulations in the seven councils, concerning costs and how they are reimbursed to the patients during the treatment. It is hoped that raising that issue at the board with representatives from all counties will result in an agreement on all-inclusive care being established for all patients. There is no ongoing systematic study in Sweden regarding patients' perspective of logistic issues.

The result of the workshop

The workshop reached consensus that Denmark's clinical approach and Sweden's research approach should be combined. The combination will optimize the systemic use of patient experiences and contribute to the development of clinical practice as well as to fill the gap of scientific knowledge of the benefits of the treatment.

Both Sweden and Denmark have similar pattern of patients living far from the PBT clinic. The importance of lowering the barriers for participation in national proton trials and proton treatment is evident. However, there is a lack of knowledge about barriers to accept PBT at a distant clinic. Further studies are needed to understand the importance of gender, socioeconomic factors, distance to treatment, level of education and diagnosis. Organizational and structural barriers related to the decision making process for PBT need to be identified as well.

The interviews with patients undergoing PBT at the Skandion clinic [22,24] revealed that receiving treatment far from their usual environment with family, friends and a familiar healthcare system was a hardship. Involving patient in systematic assessment of treatment-related toxicity and everyday care may serve as basis for optimizing the care in the context of PBT, at both the individual and the organizational level.

The suggestion for new PBT clinics is to provide for patients to meet nurses regularly during treatment, for systematic assessment of need of emotional and physical support. The nurse can provide advice for self-help or arrange a referral to other professions. A plan for the transition back to the home county, with information on whom to contact and information on possible late side effects, need to be facilitated. The patients need to know the date for the follow –up visit at the home hospital and get a structured assessment of further rehabilitation need.

Scientific evidence of the effect of PBT on PRO need to be collected for all treated diagnoses both in long and short term to gather scientific evidence of the effect of PBT as well as the cost-effectiveness of this expensive treatment.

Discussions

The results of the workshop showed a difference in how Denmark and Sweden approach the patients' need of rehabilitation and support in connection to PBT. In Denmark the patient perspective has guided the development of care since the advent of the clinic. A structured approach of collecting data from the patients and healthcare professionals has been the foundation of the clinical practice and the symptom management, which may have an impact on the relationship between the patient and healthcare staff. In Sweden the PTSG was founded to describe and compare the experience of symptoms and the impact on HRQoL of the patients undergoing PBT or CRT and to evaluate the quality of care at the Skandion Clinic. Both approaches have limitations. The clinical focus of the DCPT is excellent for their local patients, but the achievement in patient satisfaction does not benefit patients outside of Denmark. The Swedish strategy on PRO research has a slow clinical impact.

In the Nordic countries, as well as the rest of the world, there is a gap between the number of patient receiving PBT, and those that could benefit from this treatment. The reasons are cost, availability, lack of knowledge of the therapy's benefits and difficulties in referring patients [31]. Further research of the evidence of the benefit of PBT, the cost- effectiveness and outcomes that are meaningful to the patients is needed. There are organizational similarities among the healthcare services in the Nordic countries: the healthcare is financed by taxes, and thus reduce the patient's financial barrier for PBT treatment. Availability can be problematic as the treatment is not available in most patient's hometowns. The lack of evidence of the superiority of PBT in several cancer diagnoses could influence the rate of referral, as well as acceptance of receiving treatment in a national clinic. To achieve health equity, these factors need to be addressed. On the individual level, educational, psychological, sociodemographic and biological factors can influence the decision to accept an unfamiliar treatment far from home. Feelings of rural marginalization, low health literacy or traditions of self-reliance and community belonging can explain the choice of treatment at the closest hospital [32]. Healthcare staff need to be aware of these possible barriers. The contact nurse [33], familiar with the local traditions as well as the PBT clinic, has an important task to be the bridge between the patient and the national clinic.

On an organizational and provider level, the professions and the referring hospital need to be aware of their own role as gatekeeper, preventing patients from making their own decisions regarding treatment and participation in research. Clinician gatekeeping violates three principles of international ethical guidelines: respect for persons or autonomy, beneficence or a favorable balance of risks and potential benefits, and justice or a fair distribution of the benefits and burdens [34].

To better understand the complexity of accepting treatment in a distant PBT clinic, further studied is needed. What is affecting the clinician's decision to refer for treatment, and what is affecting the patient's decision to accept treatment? With more knowledge we could tailor interventions to improve the possibility of more equal healthcare in the Nordic countries.

A limitation of the workshop were that no patients' representative attended. With the research from PCSG, the patients' experiences of being treated at the Skandion clinic were represented. In future workshop, patient representative from participating countries will be invited. A further limitation is the relatively short meeting for discussions about questions of high complexity and planning for future collaboration. However, the time was well spent and important steps for the continuing work was taken.

Conclusion

This was the first workshop to discuss 'Patients' perspective in proton beam therapy' in the Nordic countries. The countries different approaches might be seen as a limitation and a demanding challenge, but gives an opportunity to learn from each other. A first workshop cannot create a comprehensive strategy to enhance the patient perspective, but this report should be seen as a first attempt to find cooperation between the Nordic countries. Future collaboration between the Nordic countries regarding patients' perspectives in the context of PBT is of importance to compare national differences as well as to find similarities, but most importantly to learn from each other and to improve patient care. Collaboration in research offers the possibility to increase the inclusion of patients' perspectives in study protocols, exchange in the development of clinical practice and to understanding inequity and barriers of accepting treatment in a national clinic of PBT.

Compliance with ethical standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Disclosure statement

The authors have no conflict of interest to disclose.

Funding

This work was supported by the Cancer Foundation in Sweden [grant numbers CAN2015/428 and CAN 2016/809].

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