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Published in:
Danish Medical Journal

Publication date:
2015

Document version
Publisher's PDF, also known as Version of record

Document license:
Unspecified

Citation for published version (APA):
Kristiansen, M., Adamsen, L., Kjær Brinkmann, F., Krasnik, A., & Hendriksen, C. (2015). Need for strengthened focus on cancer rehabilitation in Danish municipalities. *Danish Medical Journal*, *62*(4), [A5045].

Download date: 26. okt.. 2020

Need for strengthened focus on cancer rehabilitation in Danish municipalities

Maria Kristiansen, Lis Adamsen, Fie Kjær Brinkmann, Allan Krasnik & Carsten Hendriksen

ABSTRACT

INTRODUCTION: Danish municipalities have recently been given a mandate to organise cancer rehabilitation services. Knowledge is therefore needed about the services provided and their utilisation. The aim of this national Danish baseline survey was to explore the availability, utilisation, content and organisation of municipal cancer rehabilitation services.

METHODS: Electronic questionnaires were sent to all 98 Danish municipalities in January 2013. The questionnaire consisted of closed-ended and open-ended questions. Descriptive statistics and contents analysis were used.

RESULTS: A total of 91 municipalities responded (93% response rate). Of these, 75% reported that they provided cancer rehabilitation services. The number of patients enrolled was below the estimated proportion of patients needing rehabilitation services. Services consisted predominantly of physical training in groups, followed by "stop smoking" courses, dietary advice, physical training guidance, patient education and individual physical training. Inequality in referral by ethnicity, age and gender was reported. Challenges encountered included low patient numbers, inadequate collaboration within and across sectors and lack of evidence-based models for cancer rehabilitation.

CONCLUSION: There is a need for increased capacity and improved alignment between patients' rehabilitation needs and the available services.

FUNDING: This study was funded by grants from 'The Centre for Integrated Rehabilitation of Cancer Patients' (CIRE), and received support from The Danish Cancer Society and The Novo Nordisk Foundation.

TRIAL REGISTRATION: not relevant.

Rising cancer incidences and advancements in treatment have triggered an increased focus on ensuring coordinated rehabilitation services to help patients cope with the physical, psychological and social consequences of cancer [1]. In Denmark, about 35,000 new patients are diagnosed with cancer annually, and by the end of 2011, a total of 235,571 people were living with or had survived cancer [2]. Rehabilitation needs differ substantially according to type and stage of cancer, treatments and co-morbidities. Correspondingly, organised cancer rehabilitation comprises a wide variety of activities including physical training, psychological counselling, information on socio-economic issues and support groups.

There is growing evidence of the effects of cancer rehabilitation on patient-assessed outcomes (e.g. quality of life) and on physiological measures (e.g. respiratory fitness) [3, 4]. Nevertheless, a substantial proportion of cancer patients face difficulties related to the identification of their needs and navigation of the available services [1, 5-10]. The growing recognition of the importance of rehabilitation is reflected in national cancer care programmes in Europe, although few studies have explored the subsequent step from policy to practice [11].

The 2012 Danish Cancer Management Programme outlines the organisation of cancer rehabilitation services to be implemented by 2013 [12]. Services are provided by municipalities and hospitals free-of-charge and for limited time periods. Municipal cancer rehabilitation is a new field in Denmark, and little is known about service delivery. We therefore conducted a nation-wide electronic survey of cancer rehabilitation services in Danish municipalities as part of a larger cross-sectional study [13]. The aim of the survey was to explore the availability, utilisation, contents and organisation of existing cancer rehabilitation services.

METHODS

Development of the questionnaire

An electronic questionnaire consisting of 29 items was developed. A combination of closed-ended and open-ended questions was chosen to solicit additional information. The questionnaire comprised items concerning existing services, specifically addressing rehabilitation needs among cancer patients; reasons for not offering these services; target groups by cancer type; timing, setting and contents of services; organisation of services, including staffing, economic resources and collaboration with public or private providers; number of patients enrolled; inequality in use across different patient groups; and needs and lessons learned in the provision of cancer rehabilitation services. Since rehabilitation needs among cancer patients may be addressed through services that are also available to other patients, we included a question covering this aspect of service delivery. When appropriate, respondents were given the opportunity to choose more than one answer to questions, and they were able to skip sections of the questionnaire that did

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Dan Med J 2015;62(4):A5045

TABLE 1

Main reasons for not providing cancer rehabilitation services.

Reason	Explanatory statement
Integrated services encompassing patients with differing diagnoses	"There are a number of services targeting broader groups of patients, but cancer patients do use them. For example, care coordinator, exercise, patient education and collaboration with patient associations"
Lack of sufficient number of cancer patients	"Dividing [services] by diagnosis is not the best option for the organisation of services in the municipality due to its small size"
Lack of economic resources and/or staff	"Staff resources and as such also economic resources and the right type of competencies"
Awaiting policies and guidelines formulated across municipalities	"We have been awaiting in vain for a centrally organised initiative that was supposed to elaborate on content and methods in the services organised by municipalities"

TABLE 2

Perceived causes for inequality in referral to cancer rehabilitation services.

Type of cause	Explanatory statement
Ethnic inequality	"The reason why we do not see many citizens with ethnic minority backgrounds, we believe, is due to their lack of language skills even though we do have interpreters available in our services. It is probably also related to their having to leave their local community where they feel safe"
Socio-economic inequality	"Cancer patients are not systematically referred by hospitals or by their primary care physicians. […] and since citizens therefore have to take action themselves, we will lose the more vulnerable groups"
	"We would really like to have more formal collaboration with hospitals. Until recently they said that they did not have the capacity needed for referring their patients to rehabilitation services. That is why I think that there is a high probability that we see the most resourceful citizens who are able to come by themselves"
Inequality according to sex	"I feel like men have to be ‚persuaded'"

not apply to them or questions they were unable to answer. The questionnaire was pilot-tested by representatives from two municipalities located in a rural and urban area, respectively; and feedback was provided by an interest group representing Danish municipalities (Local Government Denmark).

Sampling frame and analysis

The persons in charge of cancer rehabilitation services in each of the 98 Danish municipalities were identified through municipality websites. In case of uncertainty, the municipalities were contacted by telephone to obtain the information. The questionnaire was sent via SurveyXact in January 2013; and it was completed by 57 municipalities within the following two weeks. Two reminders (one written; one by telephone) were sent. Data collection was completed by April 2013.

Data were analysed using descriptive statistics in Excel. Answers to open-ended questions were coded using contents analysis. We compared the number of patients enrolled in rehabilitation as reported by each municipality with the estimated number of patients needing rehabilitation for each municipality using data published by the Danish Cancer Society in the form of an interactive map of all Danish municipalities [14]. For each municipality, the map gives total population numbers, annual cancer incidence, prevalence and mortality estimates as well as an estimate of number of patients needing rehabilitation services.

Ethical considerations

The study was approved by the Danish Data Protection Agency (J No. 2013-41-1478). All data are kept confidential and will be deleted upon completion of the study.

Trial registration: not relevant.

RESULTS

A total of 91 completed questionnaires were returned, yielding a response rate of 93%. The municipalities included cover 92% of the Danish population.

Availability, contents and organisation of cancer rehabilitation services

Among responders, 75% (n = 68) reported having rehabilitation services specifically targeting cancer patients. The majority (n = 49 or 72%) reported that services were not available to patients with other diagnoses.

The 23 municipalities (25%) which reported that they did not provide rehabilitation services addressing cancer patients' needs were asked to describe the main reasons for this. Almost half (n = 10) responded that they were in the process of planning such services. The main reasons for not offering cancer rehabilitation are presented in **Table 1**.

A total of 51 (56%) respondents reported that they needed support to provide cancer rehabilitation services; 21 (23%) had no such need, and 19 (21%) responded "Unknown" to this question. Respondents requested, in particular, evidence-based models and tools for developing, implementing and evaluating rehabilitation services; improved economic and staff resources; a higher number of patients, in particular in rural municipalities; and improved cross-disciplinary collaboration within municipalities and at the interface between hospital-based and municipal rehabilitation services.

Among the 68 municipalities currently offering cancer rehabilitation services, a total of 66 respondents answered questions related to the contents of the services offered. Physical training in groups was reported most frequently (98%), followed by "stop smoking" courses (80%), dietary advice (80%), physical training guidance (71%), patient education (65%) and individual physical training (64%) (**Figure 1**).

A total of 15 (16%) respondents stated that they collaborated with other municipalities, e.g. in shared provision of services or courses for staff.

Utilisation of cancer rehabilitation services

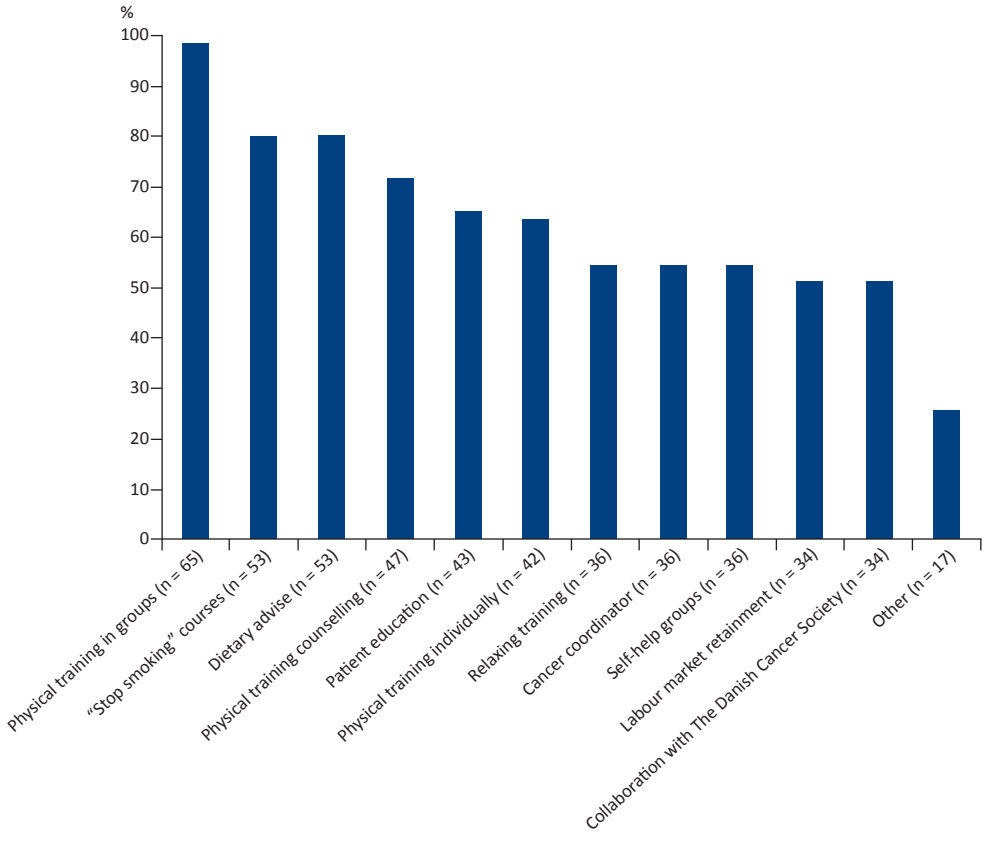
Among municipalities offering rehabilitation services, 28 reported having included 1-25 patients; 11 included 26-50 patients and the remaining 13 municipalities included more than 50 patients. Unsurprisingly, more patients were enrolled in municipalities within urban settings. When responses from each municipality were compared with the estimates provided by the Danish Cancer Society; only 13 out of the 91 municipalities had included the number of cancer patients who expectedly needed rehabilitation in 2012.

Among the 68 municipalities involved in cancer rehabilitation, 11 (16%) reported no particular inequality in the referral to services across groups of patients, whereas 27 (40%) responded "Unknown" to this question. Inequality in referral across ethnic groups was observed by 22 respondents (32%). A total of ten respondents (15%) perceived younger cancer patients to be less likely to be referred and seven respondents (10%) observed lower referral rates for males. Open-ended questions explored causes for these referral inequalities (**Table 2**).

DISCUSSION

In Denmark, hospitals and, increasingly also municipalities, are key providers of rehabilitation services, and it is therefore important to study the changing landscape of cancer rehabilitation. Using self-reported data, our study showed a relatively high number of cancer rehabilitation services in Danish municipalities, with 75% of the respondents reporting having one or more rehabilitative services that specifically target cancer patients. A report building on feedback from local representatives of the Danish Cancer Society found that an even higher propor-

FIGURE 1



Most common rehabilitation services offered by Danish municipalities (N = 66).

Cancer patients participating in physical training as part of a comprehensive cancer rehabilitation programme in Copenhagen, Denmark.

tion (87%) of municipalities either provides or plans to provide cancer rehabilitation services [15]. The differences in results may be due to either real changes in the level of implementation of cancer rehabilitation or methodological differences as our survey was completed directly by the municipalities. The reported contents of services – which emphasises physical training, smoking cessation and dietary advice – corresponds well with published findings from the Danish Cancer Society [15].

Our data do not allow qualitative assessment of the services provided. Nevertheless, as rehabilitation needs comprise a variety of physical, psychological and social aspects, more multidimensional services that target diverse needs among patients and their families may be warranted. Patient stratification by need is a prerequisite for this process to take place efficiently. Additionally, there is a need for enhanced collaboration between municipalities, in particular in areas with a limited number of cancer patients. Despite the high reported availability across municipalities, the number of patients enrolled in services during 2012 was reported in most cases to be below 50. We are unable to verify these estimates due to lack of routinely collected data on municipal rehabilitation services in the Danish registries. In general, estimating the proportion of cancer patients in need of rehabilitation is difficult, and our results should be interpreted with caution because of the lack of robust data in this field. In an attempt to capture gaps between the reported number of patients enrolled in rehabilitation services and the estimated number of patients in need of such services, we used municipal-level estimates from the Danish Cancer Society [14]. Since these data only include newly diagnosed cancer patients, the proportion of patients with unmet needs is likely to be even higher. This finding is supported by a range of studies documenting unmet rehabilitation needs among cancer patients [5-10].

Differences in utilisation across groups of cancer patients were reported with specific reference to ethnic minority groups, young patients and males. Young cancer patients may experience specific difficulties related to identity and social relationships, which indicates a need for rehabilitation programs that accommodate the specific needs of this patient group [16]. Under-utilisation of services by ethnic minority groups may be due to a lack of referrals, limited awareness of services and cultural and language differences [17]. Finally, gender-specific services are warranted [18]. We anticipated a higher number of respondents mentioning socio-economic status as a factor impacting service utilisation. However, since our data are based on self-reported perception of utilisation rather than observed characteristics of participants, results should be interpreted with caution. Systematic screening for rehabilitation needs is important to minimise the reliance on self-referral and associated differences in utilisation due to patient characteristics such as ethnicity, age and gender [9, 10, 19].

Danish municipalities have different starting points for organising cancer rehabilitation services, and may benefit from closer collaboration, thereby pooling resources and securing a sufficient numbers of patients. Cross-sectorial collaboration would facilitate a stronger evidence-base, development of patient stratification tools, and importantly help patients transfer seamlessly between sectors. This would lead to improved organisation of cooperation and clearer delineation of the areas of responsibility of municipalities, primary care practitioners and hospitals. Finally, municipalities may benefit from establishing public-private partnerships with e.g. local cancer societies.

Strengths and limitations

The response rate of this survey is very high (93%). Respondents covered approximately 92% of the Danish population, and the seven municipalities that did not participate were diverse in terms of setting (rural/urban) and size. However, as data were self-reported, we are unable to verify whether they reflect the actual state of cancer rehabilitation services in Danish municipalities. An attempt was made to validate interpretations of key concepts, most notably the conceptualisation of "rehabilitation services addressing cancer patients' needs" by asking respondents to describe the concept in a free-text comment. Also, additional questions tapping into the existence of cancer rehabilitation services were included to capture services that were not exclusively available for cancer patients. Nevertheless, data should be interpreted with caution as self-reported data may suffer from reporting bias. Furthermore, although free-text comments provided information that complemented responses from survey-items, there was a lack of detail in some areas, particularly related to the contents of

interventions. Qualitative interviews with service providers could complement our findings. There is a need for systematic data collection related to characteristics of patients utilising rehabilitation services and for patient-reported and objective outcome measures (e.g. functional ability or quality of life) [10, 19, 20].

CONCLUSION

This explorative study based on self-reported data from Danish municipalities shows a number of encouraging developments with regard to the municipalities' commitment in the provision of cancer rehabilitation services. Our study does not allow us to determine to which extent these services are aligned with the complex rehabilitation needs among cancer survivors; nor can we assess the quality of the services provided. Nevertheless, the study accentuates the need for expanding the availability and scope of cancer rehabilitation services and ensuring their acceptability among diverse patient groups.

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ACCEPTED: 30 January 2015

CONFLICTS OF INTEREST: Disclosure forms provided by the authors are available with the full text of this article at www.danmedj.dk

ACKNOWLEDGEMENTS: We would like to express our gratitude to the representatives from two municipalities and representatives from Local Government Denmark for their participation and feedback during the pilot testing of the questionnaire.

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