

## Primary care for young adult cancer survivors: an international perspective

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### Abstract

**Purpose** Internationally, family physicians (FP) are not routinely involved in young adult cancer (YAC) care. In this short report, we would like to make a compelling argument for primary care involvement.

**Methods** Comparative descriptions and literature review.

**Results** Cancer among YAs is rare and usually not the first thing that comes into the FP's mind. Youth is sometimes mistakenly regarded as a protective factor. Across the countries, almost all YACs are treated in tertiary health care facilities with specialists providing the majority of care. Health care services are covered by the universal health insurance in Denmark, The Netherlands, and Canada but not in the US. Once the YAC has completed acute treatment and follow-up care, they often return to the care of the FPs who may potentially be expected to deal with and take action upon any possible medical, mental health, and psychosocial issues the YA cancer patient may present

with. The role of the FP in follow-up care seems to be very limited.

**Conclusions** YACs in the western world seem to have comparable medical and psychosocial problems. However, the nature of health insurance is such that it impacts differently on the care of this group of cancer patients. Primary care features such as patient-centered, integrated, and comprehensive care over extended periods of time bring the FP into the unique position to provide follow-up for YAC. However, this will require integrating patient's perspectives on their care, professional continuing medical education (CME) initiatives, and an enhanced cooperative effort between those delivering and coordinating cancer care.

**Keywords** Cancer · Young adults · Primary care · Survivors · Family practice

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### Introduction

International epidemiological studies show an increase in cancer incidence as well as poorer treatment outcomes among young adult cancer patients (YAC) compared with other groups. Although, the significant mortality rate among YACs has decreased, it is still higher compared to the reductions in mortality seen among other age groups [1–3]. The reasons are multifactorial. Biological differences, intolerance to therapy, treatment by physicians who are often unfamiliar with this age group, disease properties, delay in the diagnostic phase, and lack of clinical trials and screening programs in younger populations are among some of the suggested reasons [2, 4, 5].

The majority of YACs do survive and live long productive, lives [6]. However, YAs are in a unique stage of life, transitioning from leaving home to living indepen-

dently. They may embark on educational and career endeavors, and some may have family responsibilities. From the limited knowledge we have, it is apparent that young adults diagnosed with cancer are presented with many challenges such as infertility and sexuality issues, education, work and workplace challenges, and relationships issues, among others. All of this occurs at a time when their peers are progressing along the road to independence, careers, and families [7]. The role of Family Practice (FP) in the care of adult and elderly cancer patients is gradually increasing in the different national health care systems and in research [8–10]. In the care of YACs, such a development is not evident despite an increase in the absolute and relative numbers of YAC survivors who will likely become dependent on FP for their long-term health care.

## Background

By comparing four different national health care systems, a picture of low involvement of FPs in YAC care becomes clear.

Across the countries, almost all YACs are treated in tertiary health care facilities with specialists providing the majority of care. The role of the FP in follow-up care seems to be unclarified and very limited, even though the FP is able to provide medical as well as psychosocial continuity care. However, emerging research suggests that primary care providers can contribute significantly to the care of YACs [6].

## Purpose

Internationally, family physicians are not routinely involved in YAC care. In this paper, we would like to make a compelling argument for primary care involvement.

## Methods

Comparative descriptions and literature review.

## Results

The results of the comparative descriptions are seen in Table 1. As cancer among YAs is rare, a malignancy is usually not the first thing that comes into the FP's mind when a young person enters the clinic with symptoms. YACs in some studies describe many visits to the FP before they are seen by a specialist or sent to the hospital. Youth is sometimes mistakenly regarded as a protective factor leading to delay in the diagnostic process [15].

The FP is often involved in the pre-diagnosis, but when diagnosed, YACs often go through an intensive treatment phase that rarely involves FPs. As soon as cancer is suspected, the young adult is referred to the appropriate specialist, and the FP is not involved with the patient during the treatment phase. The FP may play an indirect role to the YAC care by caring for the parents, partners, or siblings of the YAC. The immediate family of YAC often present with depression, anxiety, sleep disturbances, and may even engage in risky behaviors such as higher consumption of alcohol, tobacco use, and disturbance of sleeping habits [16].

Once the YAC has completed acute treatment and an unspecified number of years of cancer follow-up care, they often return to the care of the FPs. Hence, the FP may potentially be expected to deal with and take action upon any possible medical, mental health, and psychosocial issues the YAC may present with. Major medical issues may be secondary malignancies, cardiotoxicity, reproductive difficulties, lymphedema, reduced lung function, cognitive impairment, fatigue, endocrine dysfunction, obesity and metabolic syndrome, thyroid dysfunction, and osteoporosis [17, 18]. Post-traumatic stress disorder has also been reported to occur among 20% of YACs [19]. Other mental health issues like anxiety, depression, difficulty with close interpersonal relationships, worries of relapse, restrictions, and threats to future health due to late effects are other issues of concern during the follow-up phase [20–23].

Health care needs and issues related to YAC vary along the continuum of care and are significant for this group; thus challenging all health care professionals in general, and FPs in particular. It is to FPs that most YAC survivors and their relatives turn to for care and support for the remainder of their lives. New studies show that the role of FP in cancer care follow-up is generally an active, though rarely formalized role [10, 15]. With regard to safety, FP versus specialist follow-up in breast cancer survivors has been demonstrated to be equally safe in both Canada and the UK [24, 25]. These studies show no difference in health-related quality of life or in time to diagnose either disease recurrence or recurrence-related serious clinical events.

In a US study, having age-specific, state of the art treatment and adequate health care insurance were the highest ranked health care needs of a YAC [23]. No comparable studies are found outside the USA, and similar needs are not highlighted in the studies regarding YACs that the authors reviewed.

## Discussion

FPs in the described countries had no formalized role related to YACs. Furthermore, no FP role for this type of

**Table 1** Health care systems of the four included countries

Country	Population	Access to health care	FP sector	YAC issues and initiatives
Denmark	5.5	Based on a principle of free and equal access for all citizens who pay for this service via taxes. Supplementary private insurance systems are relatively small, but growing [11]	Deals with general health problems and its services are available to all. The FPs act as “gate-keepers” with regard to hospital treatment and specialist referral. It is normally necessary to be referred by a FP provider to a hospital for medical examination and specialist treatment, unless it is a question of an accident or an acute illness	One hospital has arranged special rooms for YACs and on a national level a resource center of youth medicine has just been opened
The Netherlands	16.5	The health care system is based on a principle of free and equal access for all citizens with a mixed public and private system; the latter is relatively small, but growing	The role of FP is similar to that in Denmark with a list system and “gate-keeping” role, but with a more formal role regarding acute illnesses	Hospitals are just starting to develop YAC outpatient departments, mainly focused on late treatment effects and secondary tumors and “life and virtual (chat) rooms” for YACs
USA	308	Patients have several avenues to access the system. Health care insurances are not mandatory but can be bought on a voluntary basis, and access to health care is controlled by the insurance companies. Emergency departments MUST provide care regardless of insurance status, but physicians/practices outside of the emergency setting are NOT obligated to do so and often turn uninsured people away. Many patients will not seek care due to financial problems	Oncologists assume care of the patient when diagnosed. In many settings, little communication with primary care may occur after the staging is done and treatment begins	Often, young adults will no longer fall under their parent’s insurance plans. Consequently, if they are unemployed, or work part time, they may not have insurance. This is a major problem among young adults in the USA who account for 17% of the under-65 population, but make up 30% of the country’s estimated 47 million uninsured [12]. The rates of uninsured young patients are worse among racial and ethnic minorities [9]. Up to two-thirds of young adults report they have not sought care, seen a specialist, or filled a prescription due to lack of insurance [13]
Canada	32	Health care costs are funded federally but administered provincially. Health care services such as doctor’s cost and hospital costs are covered by the universal mandatory health insurance in Canada. However, provincial disparities exist. Some poorer provinces may lack specialist or lack up-to-date equipment	As in Denmark and the Netherlands, the FP provider plays the role of “gate-keeper”. Patients will have to have a referral to visit a specialist  Although research indicates that cancer follow-up care can be safely provided by the family physicians, many patients feel comfortable with specialist care and will “hang on” to it until the specialist turns the care over to the family physician [14]	Additional health care-related costs, such as drugs outside of the hospital setting and other therapies must be paid for by the patients. Supplemental health insurance will cover many of these costs, but many young adults do not have such supplemental insurance. Cancer in the YA is a rare condition and they are often referred to a specialist for acute treatment and follow-up care outside of the province. As such, high transportation costs may occur  There exist few, if any, specialized cancer clinics to deal with this age group in the Canadian cancer system

care has been found in any of the worldwide literature reviewed by these authors. Some recent studies have indicated that FPs desire an active role in the follow-up care of YACs [6, 9, 26]. In sum, FPs are willing and able to

deal with the medical and psychosocial issues that YACs may face and should be considered viable options for follow-up care beginning shortly after primary cancer treatment is concluded. For follow-up, integrative and

systematic aftercare for cancer survivors' various guidelines are being proposed in the UK, Denmark, the Netherlands, Canada, and the USA [27, 28].

The described national health care systems are each unique and represent different cultures and traditions. The strengths of the Danish, Dutch, and Canadian systems are the free and equal access for all. In the US system, it is the direct access to specialists for those who are insured. A weakness of the US system is the lack of universal insurance; thus, lack of affordable insurance is a source of concern among YACs as well as frequently pronounced delays in the diagnostic and treatment phases for many of the uninsured. Other general challenges to overcome are the deficit of clinical/translational research in YACs, challenges of providing psychosocial supportive care, lack of dedicated facilities, and formalization of the role of FP in cancer care.

Despite diverse health systems, findings regarding the unique needs of YACs are generally internationally comparable. CME for FPs are becoming increasingly in focus in cancer care and follow-up, and their role is currently being debated.

#### Conclusion and future directions

YACs in the western world seem to have comparable medical and psychosocial problems. However, the nature of health insurance is such that it impacts differently on the care of this group of cancer patients. Canada, Denmark, and the Netherlands all have universal health care systems that ensure equal access for all citizens. However, additional health care services access varies from country to country, particularly impacting psychosocial care. The USA has perhaps the best care available for this age group; however, only the insured can benefit from this. Because the USA does not have compulsory health insurance, a large group of patients, particularly young adults, are uninsured.

Primary care features such as patient-centered, integrated, and comprehensive care over extended periods of time bring the FP into the unique position to provide follow-up for YAC, their partners, and family members. Models of shared care which stress co-involvement of primary care providers and oncologists throughout the cancer treatment trajectory have already been proposed [29], showing promising results, especially in countries where most citizens have a primary-care physician. Defining a primary care-based research agenda and performing relevant studies of YACs in primary care settings can support and strengthen an evidence-based approach to this model of care.

FP can and will play a significantly greater role in caring for patients with a history of cancer. It will require patient's perspectives on their care, professional CME initiatives,

and an enhanced cooperative effort between those delivering and coordinating cancer care.

#### International recommendations for cancer care of YAC in primary care

PC will inevitably assume treatment of YAC in order to manage general preventive health or co-morbid conditions at some point during the prolonged survivorship phase. It is therefore advisable that they be involved from the outset of cancer care. Medical education, both pre- and post-doctoral, will need to begin to integrate more knowledge regarding the psychosocial and biomedical late and long-term effects of cancer and its treatment in order to prepare these clinicians for this role. Improved integration of primary care into cancer centers, either via elective rotations for residents in training, or as part of a multi-disciplinary care team, may improve the quality of care delivered. With the lesson in mind that age is not always a protective factor, evidence-based guidelines for FP on diagnosis and care for YAC as well as survivorship guidance needs to be developed. As this paper has shown, much can be gained from international collaboration in this field.

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**Conflict of interest** None

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