



Research Article

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Building Consensus for the Follow-up of Colorectal Cancer Patients by Primary Care: A Nominal Group Technique Study

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Abstract

Background: In Portugal colorectal cancer has the highest number of new cases per year and cancer survivors five-year after diagnosis.

While the number of cancer survivors increases, follow-up is perceived as the management of a chronic disease.

Objective: To evaluate the viability of colorectal cancer patients' follow-up in the primary care setting.

Materials and Methods: The identification of colorectal patients who can be referred to the primary care for follow-up, the preferential follow-up model and which conditions need to be in place to secure the follow-up of those patients in the selected model was performed by a Nominal Group Technique.

Results: The definition of a clinical pathway and identification of organizational and familial systems are critical. The objectives of the follow-up need to be clarified and need to be both patient and survivor centred.

Discussion and Conclusions: Shared-care follow-up should take a multidisciplinary and survivor-centred approach, ensuring that information and communication are shared between settings with a clear definition of responsibilities, a survivor care plan and mechanisms for future referencing when justified. The complexity of cancer management can induce fragmentation and duplication of services. A cancer survivor could experience comorbidities resulting from therapeutic decisions' side effects that transform their survival in a challenge, requiring an integrated approach between different specialities. Shared follow-up has the potential to help cancer survivors to cope with their disease from a physical, social, and psychological aspects.

Keywords: Chronic disease; Colorectal neoplasms; Critical pathways; Delivery of health care, integrated; Follow-up studies; Survivorship

Lay Summary

The worldwide incidence of cancer is increasing. In Portugal colorectal cancer has the highest number of new cases per year and cancer survivors five-year after diagnosis.

Cancer has a significant impact in patients physical, emotional, and social wellbeing.

While the number of cancer survivors increases, follow-up is perceived as the management of a chronic disease.

This research aimed to evaluate the role of primary care physicians in the follow-up of colorectal cancer patients, to determine which patients with colorectal cancer could be followed up by general practitioners, the preferred follow-up model and which conditions should be guaranteed to ensure follow-up according to the preferred model.

The main findings indicate that a need to define a clinical pathway (what should happen to the patient), clarify the follow-up objectives, identify a discharge cut-off from hospital to primary care, and a higher focus on survivorship are essential. A shared-care model was considered the best suited and essentially is the result of a higher proximity of care.

It is recommended that hospital and primary care physicians and cancer survivors together define a follow-up program and a process for patient-centred care aligned with follow-up expectations as well as educational materials for survivors and families.

Introduction

In Portugal colorectal cancer is the first most common cancer, with an incidence of 10,270 new cases annually and a 5 year - prevalence of 27,627 cases [1]. In 2018, colorectal cancer in Portugal was responsible for 4,214 deaths [1].

In Occidental countries colorectal cancer survivors account for a considerable number of cancer survivors [2]. Cancer survivors living longer will be at higher risk of long-term and late effects. Cancer has a significant impact in patients' physical, emotional, and social wellbeing and is associated with a significant societal and economic impact due to premature deaths and loss of productivity because of significant morbidity and disability disease generated. In the European Union, the costs associated with cancer in 2009 were 126 thousand million euros and the costs due to loss of productivity by premature death were 42.6 thousand million euros. In Portugal, these costs were 2.05 thousand million euros, representing 1.22% of GDP [3]. Another research found that the cost of follow-up per colorectal patient in a Portuguese University Hospital was in average EUR 2,444.85 (EUR 510.62 to 4,918.79), with an average adjusted annual cost of EUR 539.09 [4].

As the number of new cancer cases increase every year, conventional cancer patients' follow-up represents a substantial burden of hospital outpatient activity avoiding physicians' higher focus in the acute phase of the oncologic disease.

The complexity of cancer management can induce some fragmentation, lack of coordination and duplication of services and produce Health Organizations with less efficiency [5,6]. A cancer survivor is a chronic disease patient who needs to cope and live with her/his disease until the end of life. In addition, these patients could experience several comorbidities resulting from therapeutic decisions' side effects that transform their survival in a personal and complex challenge.

There is growing evidence suggesting that the follow-up of cancer patients, performed by primary care is as effective as the follow-up performed by hospital specialists and is associated with gains in patients' satisfaction and reported subjective health [5,7]. The same applies to colorectal cancer when compared the follow-up by general practitioners and surgeons [8]. Other studies demonstrated a significant benefit in follow-up by primary care, by less advanced disease, fewer preoperative complications, fewer examinations by hospital specialists [9] and an improvement in subscales such as role functioning, emotional functioning and pain, and cost savings due to lower consultations' costs and fewer trips to hospital [10].

Another advantage of follow-up by primary care is to allow oncologists to focus on the acute phase of disease [11]. Despite general practitioners believe that follow-up by hospital specialists is key in case of recurrence, they are willing to assume follow-up immediately or 1-3 years after the completion of the treatment [12-15].

More and more, alternative follow-up models to the hospital centred approach are encouraged with patient's involvement in decision making, however some patients continue not having the opportunity to actively participate in the selection of the follow-up model which can be more suitable for them [16,17].

Conventional follow-up accounts for a substantial burden of hospital outpatient activity and the perceived benefit is now in debate regarding the early diagnosis of recurrence and improvement of survival [18].

The challenges related to human resources and the organizational model of care delivery to cancer patients, ensuring the ability to respond adequately in the time recommended as acceptable in quality care, as well as the associated economic impact, have emerged as central themes and place primary care as key in the follow-up of colorectal patients.

Objective

The general objective of this research was to evaluate the role of primary care in the follow-up of colorectal cancer patients.

The secondary objectives were to determine which patients with colorectal cancer could be followed up by primary care practitioners (clinical, sociodemographic and other characteristics), to determine the preferred follow-up model for the Portuguese reality and which conditions should be guaranteed to ensure follow-up according to the preferred model.

Material and Methods

Literature research strategy

A B-On (Online Knowledge Library) comprehensive literature search was carried out using the following key words: "integration of care in oncology", "integrated disease management in cancer", "cancer patients follow-up", "colorectal cancer follow-up", "cancer survivorship" and "colorectal cancer primary care follow-up". We selected 110 articles with available full text and related to the research topic.

Nominal Group Technique

The identification of colorectal cancer patients who can be discharged to primary care for follow-up, the preferential follow-up model and which conditions must be guaranteed to ensure these patients' follow-up according to the selected model was performed by Nominal Group Technique, which uses a combination of qualitative and quantitative techniques and intends to produce consensus around relevant information about a subject.

A meeting took place in NOVA National School of Public Health using an expert panel composed of two oncologists, a gastroenterologist, a surgeon, two family physicians, the head of Oncology South Registry and the President of Europacolun Portugal. The participants are well known national experts in the field of colorectal cancer, cancer epidemiology, primary care clinical governance or patient's association who may add valuable insights and have been selected due to their relevance for this research. All the participants signed a participant consent given permission to register and record their declarations and comments with the exclusive purpose of analysing them while compiling results and preparing the conclusions. The sample size was defined as per nominal group technique recommendations.

The meeting started with a brief introduction to the topic, presentation of the meeting objectives and three questions by the first author, a pharmacist by training, hospital manager. All the discussions were conducted and co-chaired with the second author, a senior researcher, assistant professor of NOVA National School of Public Health and senior hospital manager.

The questions predefined were the following:

- Which patients with colorectal cancer can be referred to Primary Care in their follow-up (clinical and sociodemographic criteria).
- What is the preferred follow-up model in our reality? a) shared follow-up b) new referral c) hospital.
- What conditions must be guaranteed to ensure the follow-up of these patients in the selected model.

We followed a four-step structure to conduct the nominal group technique:

1. **Generating ideas-** The first author presented the question in written form and read it to the group. The participants wrote ideas in brief phrases and worked independently.
2. **Recording ideas-** Participants were engaged in a round feedback session but without debate. The first author wrote the idea from each participant, visible to the entire group, until all participants' ideas had been recorded.
3. **Discussing ideas-** Each recorded idea was discussed by the group for clarity and determination of the importance.
4. **Voting on ideas-** Participants vote privately to prioritize the ideas by writing the five most important items from the

group list, with the most important receiving a rank of 5, and the least important receiving a rank of 1. Votes have been scored to identify the ideas rated highest by the group which corresponded to the ideas in response to each of the questions.

After the meeting the first author analysed each poll results, each participant's audio recording, quotes, and field notes. To ensure rigor and increase authenticity, data and results have been sent to the other authors and the group members for checking and validation.

Results

The panel listed twenty ideas about which patients with colorectal cancer can be referred to Primary Care in their follow-up, including the identification of clinical and sociodemographic criteria (Table 1) and prioritized five. The consensual results obtained by the national expert panel identified the clinical pathway as a critical factor, that is, what should happen to the patient, with an available integrated clinical record followed by the identification of the organizational and family system criteria (Table 2). It was considered fundamental to clarify the objectives of the follow-up program, which needs to be patient centred, with the assessment of the risk linked to the disease and the time since diagnosis, being that in case of high risk of recurrence (rectum carcinoma, surgery R1 and R2 and familiar risk of colorectal cancer), patients must maintain a connection to hospital due to the high specificity of the vigilance program. The definition of the follow-up cut-off and what must happen to the patient comes in third place. Additionally, there was the question of professional management of patient clinical data and access specific to the hospital setting, as well the fact that nowadays, follow-up does not focus a lot on survivorship. The patients considered eligible for shared care were all the patients with adenocarcinoma of the colon treated with curative intention stages I, II and III, without therapeutic incapacitating sequelae and a life expectancy greater than 5 years, with a functional state which will allow surgery for metastasis resection in case of recurrence. The recommendations regarding the organizational and family systems are based on very well-organized channels between the primary care practitioner and the hospital team beyond clinical history sharing, a shared-care model with a protocol agreed on by both settings, having primary care managing the regular and periodic exams which require multiple journeys to hospital and the hospital managing easy access to technology and comparative exams when required.

A. There must be a definition of a clinical pathway (what should happen to the patient) - Integrated clinical care process. Maintenance or surveillance phase (post chemotherapy or radiation therapy).
B. Must have a family doctor.
C. Risk weighting.
D. Existence of organizational system criteria: shared-care with care protocol accepted by the primary care and hospital (PC ensures regular periodic examinations that require multiple visits to the hospital, while examinations that require easy access to technology and comparative examinations in hospitals: colonoscopy, imaging).
E. Elaboration of clinical protocols and collaboration of care; it is necessary for the patient to have a family doctor or safe guaranteed inter-replacement solutions; shared care as long as hospital information is available to primary care.
F. Clarify objectives of the surveillance follow-up program. Centred on the patient and not on the interests of the Institution. Weighting between risk associated with the disease and time since the beginning of the disease. In case of technical issues or high-risk disease recurrence, patients should be connected to the hospital (e.g. rectal neoplasia, R1 and R2 surgery, family risk - very specific follow-up program).
G. Key the determination of the pathological staging of the disease (whether to make adjuvant or not) to define the type of follow-up and when it occurs, discharge to primary care and within this specifically the hereditary cases.
H. Need of organized channels of connection between the family doctor and the hospital team in addition to the transmission of clinical history.
I. It must coincide with hospital discharge (5 years without evidence of the disease) and as long as the patient is followed up in continuous care and the conditions are created for him to participate in the process (lack of patient confidence, namely about family doctor's knowledge about cancer and loss of access and connection to the doctor who healed him).
J. If the criteria for hospital discharge are defined, it is necessary to create the conditions- management of hospital discharge = critical moment.
K. First, what is expected from the follow-up of patients. Is it useful? To do this, there must be, from the beginning of the treatment, a therapeutic and follow-up plan very clear shared by all. Once the connection channels are easy. It should include the expected sequelae and complications and sensitive subjects such as incontinence. Proximity hospital can assist specialized hospital and primary care.
L. Patient is better left to the family doctor because he sees him as a whole and manages to integrate the shortcomings and disabilities.
M. Clinical criteria for intensive follow-up in shared care: all patients with colon adenocarcinoma treated with curative intent, stages I, II, III, without disabling therapeutic sequelae and life expectancy greater than 5 years and with functional status that allows them to be subjected to a metastasis resection surgery (exclude patients with cancer of the rectum or post-therapeutic sequelae that must be followed periodically in the hospital with information for the family doctor, without conditions for resection surgery followed by primary care with referral to the hospital in case of relapse).
N. Clinical criteria defined by oncologists with protocol elaboration case by case.
O. Definition of risk / benefit based on clinical criteria. Shared care: issue of professional information management and proper access to the hospital environment, like the screening program. Question of the specialization of follow-up, whether in the hospital or in primary care, which is not based on survivorship.
P. Stage I and IIa without adjuvant therapy versus stage II with risk factors and stage III with separate adjuvant therapy, rectal cancer and hereditary cancer. If immediate sequelae of treatment and late sequelae the regularity and surveillance differ. Even considering the immediate effects, knowing them in each case and thinking of distance (home, hospital, health centre) not only physical distance but also what is the most convenient for the patient.
Q. Family support and proximity structures must be considered when transferring; support that the health and family centre can give.
R. Sharing the process and what is expected globally to happen in this triangle. Personalized information management. Access has to do with what you do for, but it also has to do with financing.
S. Definition of the follow-up cut-off and what should happen to the patient.
T. Criteria (professional information, clinics, access).

Table 1: List of group ideas, before voting, about the question: Which patients with colorectal cancer can be referred to Primary Care in their follow-up (clinical and sociodemographic criteria)?

Description	Sum
A. First, there must be a definition of the clinical pathway (what should happen to the patient) - Integrated clinical care process. Maintenance or surveillance phase (post chemotherapy or radiation therapy).	36
B. Criteria of the organizational and family system.	33
C. The general idea is that it must coincide with hospital discharge (5 years without evidence of the disease) or as long as the patient is followed in continuous care and the conditions are created for him to participate in the process (lack of patient safety, particularly regarding knowledge family doctor about this pathology and the loss of access and connection to the doctor who healed him).	23
D. If hospital discharge criteria are defined, conditions must be created: discharge management = critical moment.	16
E. The patient is better left to the family doctor because he sees him as a whole and manages to integrate the shortcomings and disabilities.	12

Table 2: List of group ideas, after voting, about the question: Which patients with colorectal cancer can be referred to Primary Care in their follow-up (clinical and sociodemographic criteria)?

The existence of a family physician or interchangeable team, family support and proximity structures were also considered essentials. The panel recommended preferentially the shared-care model, which offers patients proximity to follow-up care (Table 3). For this, the existence of a pathology/cancer disease plan shared with everyone from the beginning, efficacious management of information sharing and efficacious access pathways, literacy, integrated care frameworks for both settings and appropriate definition of expectations regarding follow-up are mandatory (Table 4).

Description	Sum
Shared follow-up	24
New referral	14
Hospital	10

Table 3: List of group ideas, after voting, about the question: What is the preferred follow-up model in our reality (a) Shared follow-up; (b) New referral; (c) Hospital?

Description	Sum
A. Defined plan for this pathology and shared by everyone from the beginning. Creation of a surveillance protocol accepted by all (Hospital, Primary Care, Patients) with clear entry criteria, risk stratification and definition of tumour marker thresholds in surveillance that lead to further investigation. Goal setting.	31
D. Effective shared information management and effective access circuits. Creation of a clinical patient management system shared between Hospital care and Primary Care that allows the monitoring of the patient's clinical status and the assessment of the objectives of the surveillance system.	20
J. Literacy. Create for the different levels of knowledge a reference framework (framework) of an integrated care process for pathology and shared among all. Adjust expectations.	19
C. The existence of an interdisciplinary and multidisciplinary team in PHCs that can guarantee continuity and safety to the patient is a condition for it to work.	16
B. Good interconnection / communication between the various actors (Hospital Team, Primary Care, Patient). Ensuring effective communication between teams.	14
I. Have a family doctor or inter-substitution team in Primary Health Care.	7
E. Proximity support (access, transport).	6
F. Guarantee of quick referral and continuity line and personalization of care (inclusion in the previous process: same doctor).	4
G. The patient feels comfortable with both teams (Hospital and Primary Care).	2
H. Access to hospital resources (oncologist-centred process versus more decentralized access policy).	1

Table 4: List of group ideas, after voting, about the question: What conditions must be guaranteed to ensure the follow-up of these patients in the selected model?

Discussion

The conclusions of the national expert panel reflect the ongoing discussion in the scientific community about the role of primary care in the follow-up of cancer patients. The need to define a clinical pathway, clarify the follow-up objectives and identify a discharge cut-off from hospital to primary care, as well as a higher focus on survivorship are some examples shared with the international literature and which have been considered essential pillars by the panel [19-21]. The moment of discharge was considered critical and is aligned with cancer survivors' concerns about the format and content of the information shared at discharge from hospital, among others [22-24]. A choice centred on a shared-care model was considered the best suited to the national reality and essentially is the result of a higher proximity of care as already identified by other authors [11,25,26] and allows a better inter-sectorial cooperation [27,28]. According to the expert panel, it requires more professional information between the hospital and the primary care setting, which can rely on information integrated systems, as also recognized by other authors [16], patients' follow-up specialization at both the hospital and primary care levels and the guarantee of a family physician or an inter-replacement team as well as a family support and survivor proximity structures. Once these requisites are assured, the experts considered that coordinated follow-up between the hospital and primary care is possible, with acceptance by all players in the network of their roles and participation. It is important to mention that for doctors the greatest challenge to this prosecution is the organizational and familial system, in which the organizational and payment model may not incentivize this approach while for the patient the major concern is to lose the connection to his doctor and access to hospital in case of suspicion of recurrence based on a patients' experience of having or not having access, the additional feeling of safety generated by the hospital and the level of knowledge which the family physician has about oncologic disease.

Limitations

The use of the nominal group technique compared with other techniques has the disadvantage of minimizing discussion, which could contribute for a limitation in the development of more complete and robust ideas. The fact that experts have been chosen based on their knowledge, experience and higher engagement with this topic can be a limitation of the study and cannot exclude the possibility of different conclusions being obtained in another context, although the conclusions in our study are completely aligned with the international literature.

In agreement with other investigators [29], we conclude that there exist three key elements: knowledge transfer, communication channels and active patient involvement.

Conclusion

The worldwide incidence of cancer is increasing, being colorectal cancer one of the most prevalent cancers. The probability of a family physician having a cancer survivor older than 65 years is one in six [30], imposing many challenges to health care organizations and professionals. The conventional follow-up approach centred only on recurrence detection, is now complemented by late side effect monitoring, identification of new primary cancers and psychological support. The goal now is to identify survivor's needs, especially in what concerns their quality of life, and identify areas for intervention to improve survivorship and cancer survivor centeredness, potentiating the value-based health care concept. New variants of follow-up are emerging and the role of the primary care in the follow-up of cancer patients is being introduced [31] as a valid option which they are willing to assume. The shared care is based on a multidisciplinary approach, engaging both hospital and primary care health professionals, inclusion of patient preferences, effective systems technology inter-operability and inter-sectorial communication allowing access to the patient's clinical information from diagnosis to treatment and follow-up, with a clear definition of roles, the elaboration of a care plan and mechanisms for future referencing when needed. For the national reality, the model which seems to provide a better answer is the shared-care model. It is recommended that hospital and primary care physicians and cancer survivors together define a follow-up program per tumour type and a process for patient-centred care aligned with follow-up expectations as well as educational materials for survivors and families.

Declarations

Consent to Participate: All the participants signed a participant consent given permission to register and record their declarations and comments.

Availability of Data and Material: The data underlying this article are available in the article.

Authors' Contributions: All authors whose names appear on the submission made substantial contributions to the conception or design of the work, analysis and interpretation of data.

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