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Cover Page Footnote
We extend heartfelt thanks to all the patients and professionals who participated in this study. Special thanks to XYZ for her linguistic corrections.

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Accompanying People Affected by Cancer in Their Return to Life After Treatment: A Report on an Experiment Conducted in Canada

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ABSTRACT

This study aims to assess family doctors' perceived needs for improved patient follow-up post-acute treatment in oncology departments, specifically focusing on the Patient Oriented Discharge Summary (PODS) for individuals living with cancer. A cross-sectional quantitative survey targeted family doctors, and a before/after exploratory study was conducted with patients to measure their needs pre- and post-PODS implementation. Twenty-one out of 42 family doctors participated in the survey (50%). Patient data was collected at three points in time: prior to PODS implementation (T1, \(n=20/30; 77\%\)), one month later (T2, \(n=20/26; 77\%\)), and six months later (T3, \(n=21/28; 75\%\)). Descriptive statistics were used for all inquiries. Results revealed that 52.24\% of family doctors lacked information from oncology teams about patient treatments and their progress, while 90.48\% received no guidance on monitoring patients for symptoms or necessary tests once treatment was completed, despite everyone expressing the desire to perform such monitoring. Family doctors recommended using standardized sheets with patient information (47\%), details of side effects (41\%), and post-treatment follow-up plans (12\%). At T1, 60\% of patients received the necessary information, at T2 95\% and 81\% at T3. Regarding instructions provided to family caregivers, satisfaction levels were 40\% at T1, 90\% at T2, and 62\% at T3. The study underscores the imperative of enhancing communication between oncology specialists and family physicians, facilitating the latter's follow-up of patients completing acute treatment. It also highlights the need for patients to be adequately prepared for the transition through effective use and sustained use of PODS.

Keywords: Healthcare, Oncology, Patient experience, Quality of Care, Patient Oriented Discharge Summary, People living by cancer, Family doctors

1. Introduction

Patient engagement in healthcare is a cornerstone for improving practices and enhancing the patient experience.\(^1\) In this context, in 2013, an XYZ health centre decided to create a committee of patients and close partners in oncology to support the institution's cancer department. In 2018, this committee recommended focusing on “survivorship,” i.e. the period following acute treatment in oncology departments. Indeed, patients and relatives observed that patients were very poorly prepared to cope with life after treatment. Among other things, patient-partners highlighted the fact that patients were suffering from side effects, including chronic fatigue, due to the treatments. They also experienced emotional difficulties after treatment, due to reduced attention from family and friends, fear of recurrence, and even fear...
of returning to work or school. To support these findings, and to confirm the data in the literature, the institution’s quality management team decided to interview 27 patients and relatives who had experienced cancer in the different areas served by the CISSS. These meetings confirmed such findings and, thanks to funding from XYZ in 2019, as part of a Bridge to home for projects, a project to improve the transition was initiated. To carry it out, a working committee made up of five patient partners and six professionals was created, and four patient-partner advisory committees in the region were set up. A partnership was also formed with an association of cancer sufferers. This project led to the development of a co-constructed intervention with 55 patient partners from all over the region, as well as oncology professionals, pharmacists, and oncology nurse navigators (ONNs). The intervention consisted of implementing three strategies (see Table 1).

The first strategy aims to equip patients and their families during treatment in the oncology department. To this end, a training program in partnership with patients was offered to ONNs to enable them to master self-care teaching techniques to help patients develop their coping strategies to promote their well-being post-treatment. Next, preparatory meetings for the transition between the ONNs, the patients, and their relatives were set up using the Patient Oriented Discharge Summary (PODS) as a discussion tool to answer their questions, help them project themselves into the next stage and ensure that they know who to turn to when faced with various problems. At the same time, a transition kit was developed in collaboration with patients and professionals. Along with textual guidance on how to manage fatigue and its side effects, the kit also includes material on “Living better with your emotions after treatment”. A learning space entitled “Life afterwards” was also created on the “Team up against cancer” website. This learning space, co-constructed in partnership with patient partners, offers access to various sources of video information, tailored to the needs of patients and their loved ones. The videos aim to help patients and their families engage in self-care and learn about the various strategies and resources available in the community to help them return to a state of well-being.

To further equip patients, a meeting with a pharmacist is scheduled before the end of treatment to ensure that they are familiar with their medication and possible side effects. One month after the transition, a peer support worker from a community organization calls patients to assess their emotional state and needs, so that they can be referred to community resources, if necessary. Lastly, promoting the dissemination of community resources prioritizes physical well-being. Nutritional advice is also prioritized in connection with a proposed physical activity program. The oncology team has joined forces with local community associations to promote the benefits of physical activity during and after treatment. As a result, patients have access to free time slots in sports centers, where physical activity professionals support exercise as a means to reduce the side effects of cancer-related fatigue.

<table>
<thead>
<tr>
<th>Target audience</th>
<th>Supporting patients and their families during treatment</th>
<th>Preparing front-line teams</th>
<th>Providing peer support</th>
</tr>
</thead>
<tbody>
<tr>
<td>– Oncology teams including institutional and community pharmacists, oncology nurse navigators, public health services and patient partners</td>
<td>Primary care physicians, oncology teams including community pharmacists, oncology nurse navigators and patient partners</td>
<td>Community organization for people affected by regional organization for people with cancer</td>
<td></td>
</tr>
<tr>
<td>– Recruitment of accompanying patients</td>
<td>– Structured interview with the family doctor by the oncology nurse navigator</td>
<td>– Recruitment of accompanying patients by the community organization</td>
<td></td>
</tr>
<tr>
<td>– Implementation of a transition planning and organization tools used by oncology nurse navigators, patients, relatives and accompanying patients</td>
<td>– Medical file shared with the family doctor</td>
<td>– One-month post-transition telephone follow-up by a PA with the help of the oncology nurse navigator</td>
<td></td>
</tr>
<tr>
<td>– Distribution of a “Bridge to Home” transition kit</td>
<td>– Intranet and extranet site with cancer resources for family members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– End-of-treatment meeting with a pharmacist</td>
<td>– &quot;Life after cancer” Facebook page</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Access to a gym for physical exercise</td>
<td>– &quot;Team up against cancer” website</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– “Life after cancer” Facebook page</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>– “Team up against cancer” website</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Video on how and where to consult a healthcare professional in the event of a problem</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The regional organization for people with cancer has teamed up with a local kinesiologist to develop projects promoting physical activity during and after cancer treatment (walking, swimming, dancing, etc.).

The second strategy focuses on preparing front-line teams to receive patients who have completed their treatment. A team made up of family doctors, oncologists, pharmacists, ONNs and accompanying patients has been set up to support patients in their transition back into the community. When patients finish their treatment in the oncology department, their medical file is systematically forwarded to the family doctor and an appointment with their family doctor is then scheduled to provide them with a form of follow-up care that is shared with the oncology team, ensuring continuity of medical care tailored to their state of health and risk of recurrence.

The third strategy is based on the provision of peer support by people who have already undergone a cancer episode and who complement the expertise of the clinical team with their experiential knowledge of the disease and use of the healthcare system. This peer support is provided by members of the regional organization for people with cancer with the support of the CISSS at the end of treatment. In addition to offering a range of activities to equip people with the tools they need to recharge their batteries, share information and help them make the best of their illness (coffee meetings, wellness days, self-help groups, and conferences), the regional organization for people with cancer has developed a telephone support service for patients nearing the end of their treatment. Patients who agree to this service can receive a telephone call one month after the end of their treatment to talk to someone who has been through the same experience.

Over the past three years, these three strategies have been implemented in various phases. This first study focuses on the first phase of implementation, which involves using and adapting the Patient Oriented Discharge Summary proposed by HEC.

This project was approved by the Research Ethics Board (REB) of the Centre hospitalier de XYZ, which acts as the reviewing REB, and authorization was granted by XYZ to carry out the project (XYZ).

2. Objectives

The first objective of this study is to assess family doctors’ perceived needs in order to better follow up on their patients after they have undergone acute treatment in oncology departments. The second objective is to assess the contribution of implementing the Patient Oriented Discharge Summary (PODS) for people living with cancer (PLC).

3. Methodology

3.1. Study specifications

For objective 1, a cross-sectional quantitative study was conducted using a survey of family doctors practicing in the region. For objective 2, a before/after exploratory study was carried out with patients to measure their needs before and after the introduction of the discharge planning organization tool (see Appendix 1). Questions 1, 2, 3 and 4 are from the Ontario Hospital Association, and question 5 is modified, with permission, from Health Systems Performance Research Network and questions 6 and 7 are drawn from the International Consortium for Health Outcomes Measurement. The content in this tool is solely the responsibility of the authors and does not necessarily represent the official views of ICHOM.

3.2. Target populations

Two populations were included in this study: (1) family doctors working in family medicine groups who follow post-treatment oncology patients and (2) people living with cancer (PLCs) who have undergone a transition.

3.3. Data collection methods

Data was collected in three stages. The first phase (T1) was carried out in April 2020 and enabled us to measure the situation before the tool was rolled out. The second phase (T2) took place in May 2020 and the third phase (T3) took place in October 2020. These phases allowed to monitor the implementation of the tool over time.

3.3.1. Phase 1 (T1) (April 2020). Target population: doctors and patients

The selection criteria for family doctors were that they practice in the region and follow oncology patients. A letter was sent by an oncologist on the hospital oncology team to a total of 151 family doctors from the Gaspé region of Quebec. These front-line physicians have a panoply of patients ranging from children to senior citizens and, as mentioned earlier,
all have followed an oncology patient. These family doctors did not have supplemental training in oncology and were not affiliated with the oncology centre. The physicians were contacted using their government-assigned email addresses. The contact information was obtained via letters to members of the Council of doctors, dentists and pharmacists of the CISSS of Gaspésie. Of the 151 physicians that were contacted, 42 family doctors opened the email inviting them to take part in the survey. It is important to note that many physicians do not check their government email addresses. Twenty-one family doctors agreed to take part in the survey (50% response rate for those who opened the email). These doctors completed a 16-question questionnaire on their practice methods, their needs in terms of monitoring post-treatment patients, and their needs in terms of oncology teams and the strategies that could be implemented to help them improve this monitoring (see Appendix 2). The questionnaire was taken from the Bridge to Home project kit. It was designed and validated by the HEC team.

The inclusion criteria for patients are: (1) to be over 18 years of age; (2) to be able to speak English or French; (3) to have completed the transition within the last six months. All patients who met these criteria were contacted by telephone to be offered to take part in the research. Ten out of the 21 people contacted agreed to complete a questionnaire co-constructed by the working committee (47% response rate). This questionnaire, entitled “The patient’s experience of moving from an outpatient setting to home,” comprises nine questions relating to the assessment of needs during the transition period (see Appendix 1).

These two questionnaires were sent by e-mail and people filled them out directly online on the RedCap platform. The questionnaires were completed anonymously.

### 3.3.2. Phase 2 (T2) (May 2020). Target population: patients

The patients surveyed are not the same as those in phase 1. They are patients who have just benefited from the intervention. The inclusion criteria for these patients were: (1) to be over 18 years of age; (2) to be able to express themselves in English or French; (3) to have completed the transition in the last six months, and (4) to have benefited from the tool. These patients completed the same questionnaire as those in phase 1. Twenty of the 26 patients approached agreed to take part in the study (response rate: 77%).

### 3.3.3. Phase 3 (October 2020). Target population: patients

Here again, the patients were not the same as those in phases 1 and 2. The inclusion criteria were the same as in phase 2 and the questionnaire administered was the same as in phases 1 and 2. Twenty-one of the 28 patients approached agreed to take part in the study (response rate: 75%).

### 4. Results

#### 4.1. For family doctors

Family doctors work in several types of organizations and are distributed across the different territories of the XYZ (see Table 2 to consult all results). More than half of the family doctors (57.15%) did not have a planned follow-up with their patients undergoing chemotherapy in collaboration with the treating oncology team. Furthermore, 52.24% of the family doctors did not receive any information from the oncology team about their patients’ treatment, even though all doctors would like to receive said information from these teams as they all consider it essential to have access to it. Of those who have received this information, 61.90% were satisfied. 95.24% of doctors received notes from the haematologist-regarding their patients’ progress. However, doctors would like better communication with the oncology team, particularly regarding the nature of the treatments and the actions to be taken to monitor patients.

At the end of the treatment, 90.48% of doctors did not receive any information on what they should do to monitor their patients, such as monitoring symptoms, carrying out tests, etc. once treatment had been completed, even though 100% of them would like to receive such information. For those doctors who do receive information, 71.42% said that the information received was insufficient regarding their patients’ follow-up. 61.90% of the information is transmitted electronically. Furthermore, 47.62% of doctors were unaware of the role of the oncology nurse navigators in the post-treatment phase of cancer care.

To improve the situation, family doctors suggested using standardized sheets containing patient information (47.05%), information sheets on side effects (41.17%), and, finally, post-treatment follow-up plans (11.76%). They also suggested improving communication between themselves and the doctors specializing in oncology (50%) and ensuring better communication of the tasks involved in monitoring
Table 2. Summary of the results of questionnaires sent to family doctors.

<table>
<thead>
<tr>
<th>Responses</th>
<th>N (total = 21)*</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is your main mode of practice as a family doctor?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private office</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>GMF</td>
<td>9</td>
<td>43</td>
</tr>
<tr>
<td>GMFU</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>CLSC</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td><strong>Which area do you work in?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area 1</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>Area 2</td>
<td>6</td>
<td>29</td>
</tr>
<tr>
<td>Area 3</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>Area 4</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td><strong>Do you provide medical follow-ups for patients who are undergoing chemotherapy during their treatment, this, in collaboration with the oncology team?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>43</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>I have seen very little of my patients since the start of treatment</td>
<td>9</td>
<td>43</td>
</tr>
<tr>
<td><strong>Do you receive clinical information from the oncology team about treatment protocols or your patient’s clinical progress?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>48</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>48</td>
</tr>
<tr>
<td>I don’t know</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>If not, do you think it is important to receive this information while your patient is undergoing chemotherapy? (N = 16)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>100</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>If yes, are you satisfied with the clinical information you receive from the oncology team? (N = 10)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Somewhat</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td><strong>Are you satisfied with the way you work with the oncology team to monitor your patients undergoing treatment?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>62</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>39</td>
</tr>
<tr>
<td><strong>Do you receive notes on your patient’s clinical progress from the haemato-oncologist?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20</td>
<td>95</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>What would you recommend to improve the information to be transferred during chemotherapy treatments? Detail your answer (N = 15)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduce the time taken to receive information</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Better communication on treatment, tasks and follow-up</td>
<td>13</td>
<td>87</td>
</tr>
<tr>
<td><strong>Do you receive clinical information about the follow-up plan (symptoms to be monitored, tests to be carried out, etc.) once treatment has been completed?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>19</td>
<td>90</td>
</tr>
<tr>
<td><strong>If not, do you think it is important to receive this information in order to continue your medical treatment? (N = 20)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20</td>
<td>100</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>If so, does the clinical information you receive from the oncology team contain enough information to help you continue your medical follow-up? (N = 7)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>No, I’d like more information</td>
<td>5</td>
<td>71</td>
</tr>
<tr>
<td>I don’t know</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td><strong>Do you work with a computerized information transfer system, and if so, which one?</strong> (each participant could choose more than one answer in this case)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>48</td>
</tr>
<tr>
<td>Electronic medical files</td>
<td>10</td>
<td>48</td>
</tr>
<tr>
<td>Fax</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Email</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>38</td>
</tr>
<tr>
<td><strong>Do you know the role of the nurse navigator in the post-treatment phase of cancer care?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>48</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>48</td>
</tr>
<tr>
<td>I don’t know</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>What recommendations would you make to improve the transfer of files to patients who have completed their cancer treatment?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of standardized sheets/information on the patient’s case</td>
<td>8</td>
<td>47</td>
</tr>
<tr>
<td>Information sheets on side effects</td>
<td>7</td>
<td>41</td>
</tr>
<tr>
<td>Post-treatment follow-up plan</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td><strong>Other suggestions?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better communication between physicians</td>
<td>2</td>
<td>50</td>
</tr>
<tr>
<td>Better distribution of tasks</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>Remind patients to do their follow-up</td>
<td>1</td>
<td>25</td>
</tr>
</tbody>
</table>

*Participants were allowed to skip questions, any question without a specified N value, have the total 21 participants responses
patients (25%), so that they could encourage patients to carry out their monitoring (25%).

4.2. For patients

Regarding the information that patients receive from professionals to prepare them for their return home following acute treatment, the majority of patients (60%) questioned had not received any information before the intervention was implemented (T1). Following the implementation of the intervention, a significant increase in patients, 95% (n = 20) felt that they had received information, and 81% (n = 20) at T3 (see Fig. 1).

In addition, at T1, 70% of patients (n = 10) felt that they had not been trained at all to recognize symptoms to look out for on their return home that might require a referral to a healthcare professional. This situation rose to 60% (n = 20) at T2 and 61% (n = 21) at T3 (see Fig. 2) after a web-based learning space was introduced and Information tools on life after cancer were provided.

At T1, 40% (n = 10) of patients understood the medication prescriptions on their prescription, whereas at T2, 80% (n = 20) understood them after the program had been set up, and 38% at T3 (see Fig. 3).

One of the questions asked whether patients knew what to do if they were worried about their illness or treatment when they returned home. At T1, 40% (n = 10) had no idea, but at T2, 85% and 67% at T3 felt well informed (see Fig. 4).

Patients were also asked if they knew who to contact if they had any concerns about their health or treatment. At T1, 80% knew who to contact, in other
words, the oncology nurse navigators, then 85% at T2 and 100% at T3 of respondents knew they could contact the oncology nurse navigator (see Fig. 5).

At T3, 81% of participants said they were satisfied with their level of participation and decision-making in their care, 9% less than at T2 (90%) but 61% better than at T1 (20%) (Fig. 6).

This trend was reinforced when patients were asked about the involvement of family members or significant others in discharge planning. At T1, only 50% (n = 10) of patients considered that their close relatives were included, whereas at T2, this situation was 70% (n = 20) and at T3, 81% (n = 21) (see Fig. 7). Furthermore, concerning the information received by family caregivers, at T1, 40% (n = 10) were satisfied, at T2, 90% (n = 20) and at T3, 62% (n = 21) were satisfied (see Fig. 8).

Finally, patients do not tend to visit emergency or outpatient departments within the 30 days following discharge at any of the three times (Fig. 9).

5. Discussion

This study responds to the need for a better understanding of the organization of this transition period, which is known to be particularly difficult for patients who are moving from a highly medicalized, structured and supportive environment to a return to normal life with less social support and a different state of health from that which they had before their diagnosis. More specifically, it is interested, on the one hand, in highlighting family doctors’ perception of their perceived needs to better monitor their patients after acute treatment in oncology departments and, on the other hand, patients’ perception of the
Fig. 5. Information received by patients from healthcare professionals about who to contact if they have questions or concerns about their health or treatment, on their return home, after hospitalization, at different times.

Fig. 6. Patient involvement in discharge planning and decisions made at different times.

Fig. 7. Involvement of family and caregivers in discharge planning and decisions made at different times.
Fig. 8. Information received by family or close caregivers at different times.

Fig. 9. Patients hospitalized in the last 30 days since discharge at different times. Legend: The questionnaire seeks to determine whether patients presented to hospital emergency departments (a), or on an outpatient basis overnight (b).
contribution of the PODS as a tool that provides access to information to meet patients’ needs once they have completed their acute cancer treatment. 15

As far as doctors’ perceptions are concerned, they stressed that they were not sufficiently involved in their patients’ post-treatment follow-up. This is reflected in various ways, such as a lack of communication with the oncology team, or a lack of information about the treatments received by their patients, or irrelevant information being passed on. These findings support previous research demonstrating that family doctors are rarely consulted about the information they need to monitor their patients. 16,17 These studies also highlight the importance of creating forums for discussion between family physicians and oncologists. 18,19 Another important point is the lack of knowledge about the composition of the oncology team and the specific role of oncology nurse navigators. 20 In XYZ, oncology nurse navigators have a well-defined role and have been introduced into oncology departments to coordinate care with the community, particularly family doctors. 21 However, having only recently been introduced, they are not yet sufficiently well known among healthcare professionals, particularly those working outside healthcare institutions. However, their role is essential in fostering fruitful collaboration between oncology specialists, nurses and family doctors. 22,23

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In general, doctors are interested to learn about the organization of cancer care and to take part in the follow-up to improve their performance. Recent transition models proposed at an international level refer to the essential role of family doctors in monitoring patients after their treatment. 24–26 This involvement ensures that patients are monitored close to home and avoids the need for ultra-specialized services for conditions that do not require this level of care. 27 Suggestions for improving communication between front-line professionals and cancer services include 1- the deployment of electronic communications between clinicians, 28,29 2- the sharing of standardized electronic summaries of treatments carried out, their side effects and follow-up plans, 30,31 and access to shared medical records. Tools to keep family doctors abreast of their patients’ progress are therefore essential, as the Institute of Medicine (IOM) points out. 32,33

As far as the patients are concerned, the results show a clear improvement between the first and second data collection sessions. This shows that the proposed tool meets patients’ needs, whether in terms of the treatments they have received, the symptoms to be monitored after acute treatment, the resources to be mobilized in light of the situations encountered, or their ability to engage in decision-making. However, the study also shows that these results decline at T3. The first hypothesis put forward relates to the time at which the patient uses the tool and the time at which the assessment is carried out. A second hypothesis is that the strategy for using the tool may have been different between T2 and T3. In fact, it is essential to plan the implementation carefully to maintain use of the tool over time by ensuring the necessary resources. 34 This study also highlights the importance of monitoring the effects of the transition tools implemented over time, not only to ensure that they meet needs but also that the methods of use are optimal. These evaluations will facilitate the implementation of continuous improvements.

6. Strengths and limitations of the study

The great strength of this study is first that it was able to monitor patients’ perceptions of the use of the tool over time. And even if the response rates could have been higher, compared with other studies, these figures are satisfactory. 35,36

As far as limitations are concerned, the study would have benefited from monitoring doctors’ perceptions over time. The fact that only one set of data was collected means that their perception cannot be measured over time. The number of respondents from doctors was also low. As for the patients, it would have been compelling to carry out a fourth data collection to see whether the T3 trend was maintained over time, or whether this was circumstantial, and the results were closer to T2. In addition, it is difficult to know whether the intervention was maintained at the same level between T2 and T3, which could explain the results.

The data collection would have also benefited from tracking the two cohorts of patients who responded at T2 and T3 to highlight possible changes over time. The literature shows that the more time passes after the end of treatment by oncology departments, the less patients know who to contact in the event of problems. 37

The results reflect the need recognized by patients to prepare for the end of treatment. Further studies can objectify the various rewards reaped from surrounding post-treatment oncology patients with the proper tools and resources at their disposal. 38
7. Conclusion

This researcher made it possible, on the one hand, to highlight the situation concerning the needs of patients and family doctors and, on the other hand, to evaluate the implementation of the tool to improve the transition between the care offered by cancer services and post-treatment follow-up by family doctors from the patient’s point of view. The project highlights the need to equip family doctors to monitor PLCs. It also highlights the need to provide information and self-care support for patients and their families, so that they can take better action to improve their well-being and reduce the risk of complications or negative repercussions of the disease and its treatment on their physical, psychological and social well-being. Planning for the organization of the end of oncology services should be implemented as early as possible in the patient’s care pathway, with the participation of patients and their families. Preparing PLCs as early as possible in their care pathway for the transition will enable them to take care of themselves, to better project themselves into the future in order to effectively anticipate the post-treatment period. The link between oncology services and family medicine requires communication channels to be created to contribute to an effective and safe transition for patients and their families.

This initial exploratory study of the use of the tool suggests that it could be implemented more broadly in XYZ, and even internationally. In addition, a XYZ-funded project has made it possible to enhance the kit given to patients at the time of transition. It is also part of a more extensive project to evaluate all the strategies implemented to improve transition in XYZ.

Acknowledgement

We extend heartfelt thanks to all the patients and professionals who participated in this study. Special thanks to XYZ for her linguistic corrections.

Conflict of interest

The authors declare no conflict of interest.

References

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Appendix 1: Outpatient transition experience (v2 April 2019)

Please answer all questions about your recent experience of transitioning home. Please check only one answer per question. Your answers are voluntary and will provide us with important information.

1. While you were in the hospital, did the doctors, nurses or any other staff member ask you if you had any help you would need after you were discharged from <clinic name>? *question required
   - Certainly
   - For the most part
   - Somewhat
   - Not at all
   - I didn’t need this type of information

2. Did a healthcare professional tell you what warning signs about your illness or treatment you should watch for at home? *question required
   - Certainly
   - For the most part
   - Somewhat
   - Not at all
   - I didn’t need this type of information

3. Before leaving the <clinic name>, did you fully understand all of your prescription medications, including those you were taking prior to your visit to the <clinic name>? *question required
   - Certainly
   - For the most part
   - Somewhat
   - Not at all
   - Not applicable

4. Did you get enough information from healthcare professionals about what to do if you were worried about your illness or treatment after you left the <clinic name>? *question required
   - Certainly
   - For the most part
   - Somewhat
   - Not at all

5. Before you left the clinic <name of clinic>, were you given contact details if you had any questions or concerns about your condition or treatment?
   - Yes
   - No
   - Don’t know/don’t remember/not applicable

6. In planning your discharge, were you as involved as you wanted to be in discussions and decisions about your care, support and treatment?
   - Certainly
   - For the most part
   - Somewhat
   - Not at all

7. Has your family or caregiver also been as involved as you would have liked in discussions and decisions about your care, support and treatment?
   - Certainly
   - For the most part
   - Somewhat
   - Not at all
   - No family members or caregivers were available to participate in discussions/decisions
   - I did not want my family or caregiver to be involved in discussions/decisions

8. Did your family, caregiver or someone close to you receive the information he/she needed to take care of you? *question required
   - Yes
   - No
   - Don’t know/don’t remember/not applicable

9. Have you been in the hospital in the last month (30 days) since your discharge from <clinic name>? *question required
   - Emergency services
   - Overnight stay in the hospital (admission)
   - Other: Please specify:

10. Other comments about your care transition experience
Appendix 2: Family doctors’ experience during their patients’ transitions from a specialized oncology setting back to primary care (April 2019)

Please answer all the questions regarding your recent experience of transition to home. Your answers are voluntary and will provide us with important information.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Your answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. What is your main mode of practice as a family doctor?</td>
<td>☐ Private office ☐ GMF ☐ GMFU</td>
</tr>
<tr>
<td>12. Which area do you work in?</td>
<td>☐ Territory 1 ☐ Territory 2 ☐ Territory 3 ☐ Territory 4</td>
</tr>
<tr>
<td>13. Do you provide a medical follow-up for patients undergoing chemotherapy during their treatment, in collaboration with the oncology team?</td>
<td>☐ Yes ☐ No ☐ I rarely see my patients since the start of their treatments</td>
</tr>
<tr>
<td>14. Are you satisfied with the collaboration with the oncology team for the follow-up of your patient undergoing treatment?</td>
<td>☐ Yes ☐ No ☐ I don’t know - I don’t remember - N/A If no, why?</td>
</tr>
</tbody>
</table>

During chemotherapy treatments

15. Do you receive clinical information from the oncology team about treatment protocols or your patient’s clinical progress? | ☐ Yes ☐ No ☐ I don’t know |

16. If no

Do you think it is important to receive such information while your patient is undergoing chemotherapy? | ☐ Yes ☐ No |

17. If yes

Are you satisfied with the clinical information you receive from the oncology team? | ☐ Detailed answer: |

18. Do you find it difficult to communicate with the doctors on the oncology team or the pivot nurse when you have questions about your patient’s follow-up? | ☐ Yes ☐ No ☐ Detailed answer: |

19. What would you recommend to us to improve the information to be transferred during chemotherapy treatments? | ☐ Detailed answer: |

After treatments

20. Do you receive any clinical information about the follow-up plan or the symptoms to watch out for once treatment has been completed? | ☐ Yes ☐ No ☐ I don’t know |

21. If no

Do you consider it important to receive such information in order to ensure continuity of service? | ☐ Yes ☐ No ☐ I don’t know |

22. If yes

Does the clinical information you receive from the oncology team contain enough information to help you continue your medical follow-up? | ☐ Detailed answer: |

23. Do you work with a computerized transfer system for clinical information? | ☐ Yes ☐ System ☐ Email ☐ Fax ☐ No |

24. What recommendations would you make to facilitate the transition of care for patients who have completed their cancer treatment? | ☐ Detailed answer: |

25. Do you know the role of the pivot nurse in the post-treatment phase of cancer care? | ☐ Yes ☐ No ☐ I don’t know |