

Development and pre-testing of a rehabilitation planning consultation for head-and-neck cancer

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ABSTRACT

Background In contrast with other major chronic conditions such as heart disease and stroke, cancer care does not routinely integrate evidence-based rehabilitation services within the standard continuum. The objectives of the present project were to develop a rehabilitation planning consultation (RPC) for survivors of head-and-neck (HN) cancer, to test its feasibility, and to make refinements.

Methods Using intervention mapping, the RPC-alpha was developed by examining potential theoretical methods and practical applications relative to the program objectives. During feasibility testing, a single case series was conducted with survivors of HN cancer who had completed their cancer treatment within the preceding 11 months; iterative refinements were made after each case.

Results The RPC-alpha was led by a rehabilitation professional and was based on self-management principles. The initial consultation included instruction in a global cognitive strategy, goal-setting, introduction to available resources, action planning, and coping planning. A follow-up consultation was conducted a few weeks later. Of 9 participants recruited, 5 completed post-intervention assessments. Participants reported that the RPC helped them to make rehabilitation plans.

Conclusions The RPC was feasible to use and satisfactory to a small group of HN cancer survivors. A pilot test of the refined version is in process.

Key Words Head-and-neck cancer, rehabilitation, self-management, cognitive strategy use, intervention mapping, program development

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INTRODUCTION

Survivors of head-and-neck (HN) cancer can benefit from rehabilitation services to address impairments (such as those affecting swallowing, nutrition, muscle strength, joint range of motion, fatigue, and pain) and to improve overall function, participation, and health-related quality of life¹⁻⁵. Despite that understanding, rehabilitation services are not routinely integrated into the cancer care continuum⁶. Access to rehabilitation for survivors of HN cancer is limited by a lack of convenient, affordable, HN-cancer-specific services; lack of awareness about rehabilitation; lack of confidence on the part of the HN

cancer clinical team about the quality and value of existing community-based services; and survivor challenges with self-advocating for services⁷. Our goal was to develop and evaluate a rehabilitation planning consultation (RPC) for survivors of HN cancer to be integrated within the existing health system⁸.

The methodology used for this development project is intervention mapping, which takes a systems approach to planning theory-based health-promotion interventions⁹. Intervention mapping consists of these steps⁹:

1. Needs assessment
2. Definition of program objectives

3. Selection of theory-based intervention methods and practical applications
4. Production and pretesting
5. Adoption, implementation, and sustainability planning
6. Process and effect evaluation

During the previously conducted step 1, we established an advisory panel consisting of survivors, cancer rehabilitation professionals (occupational therapy, psychiatry, physiotherapy, and speech–language pathology), and health system representatives. The advisory panel was consulted at all key development junctures. We used literature review, focus groups, and advisory panel input to establish the rehabilitation needs of survivors, a preliminary version of which is published in the research protocol for the present project⁸. In the previously conducted step 2, the investigative team and advisory panel defined these objectives for the RPC:

- Determine the priority rehabilitation needs of survivors
- Set goals and action plans related to the priority rehabilitation needs
- Facilitate implementation of, and necessary adjustments to, action plans to meet goals

Here, we report on intervention mapping step 3, selection of theory-based intervention methods and practical applications, and step 4, pre-testing.

Intervention Mapping Step 3

In intervention mapping step 3, potential theoretical methods and practical applications are examined relative to the desired program objectives. In our case, we worked from *a priori* practical decisions that the intervention should be brief, readily embedded within the existing cancer care system, and founded on self-management principles. Self-management—the process by which people with chronic conditions learn the skills necessary to independently lead an active and satisfying life¹⁰—emanates from Bandura's social cognitive theory¹¹. Based on key contributors to self-management identified by Boger *et al.*¹², we established four determinants for the RPC objectives: cognitive strategy skills (for example, goal-setting, action planning, and decision-making), self-efficacy, positive relationships with health professionals, and access to resources.

Theory-Based Intervention Methods

We considered a broad repertoire of theoretical methods taken from our own repertoires and from Bartholomew *et al.*'s tables⁹. Iterative discussions between the research team members reduced the initial list to key theoretical methods (Table 1).

Theoretical Methods to Improve Cognitive Strategy Skills:

The primary theoretical method adopted to facilitate improvement in cognitive strategy skills was global cognitive strategy training. Global cognitive strategies, also called metacognitive or general strategies, provide structured frameworks for action planning

and decision-making, have a self-monitoring component, and can be used in almost any situation in which problem-solving is required¹³. Specifically, we selected a global cognitive strategy used in the co-op approach (“cognitive orientation to daily occupational performance”)¹⁴, which has been successful in improving skill performance in several rehabilitation populations^{15–18}. The strategy Goal-Plan-Do-Check¹⁹ involves defining a goal (a collaborative process between therapist and client to develop a plan), following the plan, and then checking to see if the plan worked. Unsuccessful plans result in iteratively guided modifications until success is achieved.

Based on our vision of the RPC, we anticipated that survivors would be on their own without therapist guidance when following through with the plan and might need assistance to anticipate barriers. Coping planning was therefore added as an additional theoretical method²⁰. Planning can be divided into action planning and coping planning: Action planning represents initial intentions, and coping planning represents the preparation of strategies to overcome barriers. Coping planning is a self-monitoring strategy that individuals can use to pre-plan a mental link between potential barriers and potentially viable solutions. Compared with using action planning alone, the addition of coping planning is associated with improved health behaviours²¹.

Embedded within the global cognitive strategy is goal-setting. Goal-setting that is collaborative and that involves the active participation of the client has been a mainstay of rehabilitation for many years. It is associated with improved goal achievement and adherence to programs^{22–24}. The involvement of the client ensures that the goals are personally meaningful, thereby increasing the motivation to act.

Theoretical Methods to Improve Self-Efficacy: Self-efficacy is confidence in one's ability to execute a specific action¹¹. Individuals might believe that a certain action will cause a desired outcome, but their doubt in their own ability to complete the action might stop them in the attempt. Thus, improved self-efficacy positively influences behavioural change. Recommended theoretical methods to augment self-efficacy include performance-based interventions that emphasize accomplishments and diminish apprehension to act, and verbal persuasion, wherein the therapist provides verbal support for the client's ability to execute activities that might have been overwhelming in the past¹¹. Additionally, an instructional method known as “guided discovery” was adopted. Guided discovery is a means of providing instruction and feedback using questions, hints, and coaching rather than explicit direction²⁵; it has been used successfully in the co-op approach (see, for example, McEwen *et al.*¹⁵ and Dawson *et al.*¹⁸). Guided discovery enhances the active engagement by the learner, thereby potentially increasing self-efficacy.

Theoretical Methods to Improve Positive Relationships:

Many of the methods already discussed are likely to enhance positive relationships with the survivor, who is engaged as a collaborator and equal partner in the intervention process²⁶. As an additional pre-emptive action

TABLE I Theoretical methods as related to objectives and determinants

		Behavioural objectives		
		Determine and prioritize survivor rehabilitation needs	Develop goals and action plans	Implement plans and adjust as necessary
Determinants	Cognitive strategy skills	—	■ Global cognitive strategy training, incorporating goal-setting, action planning, and coping planning	■ Global cognitive strategy training, incorporating self-monitoring, action planning, and coping planning
	Self-efficacy	■ Performance-based intervention ■ Verbal persuasion ■ Guided discovery	■ Performance-based intervention ■ Verbal persuasion ■ Guided discovery	■ Performance-based intervention ■ Verbal persuasion ■ Guided discovery
	Positive personal relationships	■ Advance organizer ■ Engaging survivor as collaborator ■ Individualization	■ Engaging survivor as collaborator	■ Engaging survivor as collaborator
	Access to resources	■ Individualization ■ Tailoring ■ Facilitation ■ Discussion	■ Individualization ■ Tailoring ■ Facilitation ■ Discussion	■ Individualization ■ Tailoring ■ Facilitation ■ Discussion

toward building a positive relationship, we adopted an advance organizer. An advance organizer is an overview of the materials to be presented⁹ and in this case also includes an overview of the process and rationale behind the RPC. Use of the organizer is intended to pre-empt frustration or confusion stemming from earlier experiences with more typical directive consultations with health professionals.

Theoretical Methods to Improve Access to Resources: Bartholomew and colleagues⁹ tabulated methods to increase knowledge and to effect change, including advance organizers, tailoring (matching the intervention to the characteristics of the survivor), individualization (providing opportunities for survivors to ask personal questions and receive pacing instructions according to their individual progress), facilitation (creating an environment that makes action easier and reduces barriers), and discussion (encouraging open discussion or debate about a topic). We aimed to apply all those methods in the RPC.

Practical Applications

We developed a framework for the development of practical applications for the RPC, specifying that the consultation will fit within the existing cancer care system, be led by a rehabilitation professional, and include a brief functional evaluation, a resource compendium, and goal-setting and action-planning processes.

Rehabilitation Professional Leadership: We named the leadership position the rehabilitation consultant (RC) and recruited with the requirement that the person

- be a trained and licensed occupational therapist, physiotherapist, or speech-language pathologist;
- have clinical experience with HN cancer;
- have a good understanding of the roles of all members of the HN cancer professional team in a comprehensive cancer centre.

For this project, we hired CD, a licensed physiotherapist with more than 10 years of experience in general oncology rehabilitation, including specific HN cancer experience and project management experience. CD delivered the RPC-alpha and was a key contributor to subsequent modifications.

Brief Functional Evaluation: Using our previously developed rehabilitation needs assessment⁸, a list of potential concerns amenable to rehabilitation was developed to help individual survivors prioritize and develop goals. That list evolved into the Brief Rehabilitation Assessment for Survivors of Head-and-Neck Cancer (BRASH). The BRASH consists of 17 physical items, 5 cognitive and psychosocial items, and 8 activity and role items. It allows for a holistic assessment of potential patient concerns across a variety of rehabilitation disciplines. For each item, the participant has the option to check one or both of “I have concerns about this” and “I would like to discuss rehab for this.” The participant also notes any additional issues of concern and which of those issues are the most important. An early version of the BRASH was examined and refined by members of the advisory panel and study investigators for face validity; it was then edited for language level by a specialist in patient education.

Resource Compendium: At <http://www.hncrehab.ca>, we compiled an inventory of general cancer and HN cancer-specific rehabilitation resources in Toronto and surrounding regions for survivors and for health care professionals alike. Resources for survivors are arranged by rehabilitation need, such as swallowing, exercise, swelling, body image, and so on. Each page contains two sections: downloadable information such as pamphlets, videos, and links to other Web sites; and information on finding a clinic, program, or class where survivors can seek in-person assistance from a rehabilitation professional. The resources for health care professionals include information and links to reputable training programs in HN cancer rehabilitation, and practical tools such as patient exercise handouts and goal-setting tools.

The Web site also includes a searchable inventory of rehabilitation programs and single-service rehabilitation professionals who have been screened by our team to have a minimum level of knowledge for working with survivors of cancer or who have agreed to partner with us in the event that we refer a patient to their clinic or program. Because one of the barriers to rehabilitation access is a lack of confidence on the part of HN cancer teams at specialized cancer centres about the quality of existing community-based services, such screening was considered crucial.

Processes

The RPC was designed to have two parts: an initial consultation with the RC to determine goals, actions, and coping plans; and a follow-up to review goals, plans, and results, and to make modifications as necessary. The initial consultation involves a face-to-face meeting. The follow-up is either a face-to-face or a telephone consultation, depending on the preference of the survivor.

RPC-alpha: We embedded the chosen theoretical methods within the practical methods and developed the RPC-alpha. Descriptions of the initial consultation and follow-up consultation processes follow.

Initial Consultation Processes:

- Orientation
A brief presentation by the RC introduces the survivor to the reason for the consultation and the process.
- Consultation
The RC implements the BRASH and discusses results. The survivor identifies the issues that are currently most important.
- Goal-Setting
The survivor and RC worked collaboratively to set goals.
- Introduction of the Cognitive Strategy
The RC teaches the survivor the cognitive strategy Goal-Plan-Do-Check¹⁸.
- Action Planning and Coping Planning
The RC uses guided discovery and verbal persuasion to facilitate the survivor to elaborate goals, plans, potential barriers, and coping plans.
- Introduction of Online Resources
The RC introduces the survivor to the online resource compendium (<http://www.hncrehab.ca>) for future use, with particular emphasis on resources pertinent to the survivor's priority issues and questions and those necessary to implement the survivor's plans. The RC makes use of facilitation, individualization, tailoring, and discussion as appropriate.
- Summary
The RC provides a written copy of goals and plans. A follow-up appointment is scheduled for 2–10 weeks

later, at a mutually convenient time. The survivor is encouraged to execute (“Do”) the plan.

Follow-Up Consultation Processes:

- Reminder
An e-mail message, text, or telephone reminder (as preferred by the survivor) about the follow-up appointment is sent approximately 24 hours in advance.
- Reorientation
The RC meets with or calls the survivor at the designated date and time. The RC reacquaints the survivor with the RPC process.
- Checking and Re-planning
The RC uses guided discovery techniques to conduct a discussion about the Do-Check portion of the global cognitive strategy. If the plan has been successfully implemented and the goals achieved, next steps are discussed. If the plan has not been implemented or the goals not achieved, the RC guides the survivor to modify the plan as necessary. A revised coping plan is also developed.
- Summary
The need for ongoing support and a second follow-up appointment is discussed, and if necessary, the appointment is scheduled at a mutually convenient time. A follow-up is deemed unnecessary if the survivor and the RC are confident in the survivor's ability to manage the rehabilitation needs independently. The survivor is provided with information about how to access the RC in the future should the need arise, and those without a need for a follow-up session are discharged.

Intervention Mapping Step 4

For pretesting and refining the RPC, these specific research questions were posed:

- Is the RPC-alpha intervention feasible to administer? (Criteria for feasibility included withdrawal rate, time to administer the intervention, and acceptability of the intervention to the client and therapist.)
- Does the RPC-alpha require modifications to improve the feasibility and acceptability of its administration?

METHODS

Research ethics board approval was obtained for both study sites, the Odette Cancer Centre and the Princess Margaret Cancer Centre. An iterative series of single case studies was used. Recruitment was conducted at the HN cancer clinics at both sites. To be eligible, participants had to be adult survivors of HN cancer who had completed active treatment with curative intent (surgery, radiation, chemotherapy or any combination thereof) within the preceding 11 months. Exclusion criteria were lack of English fluency, cognitive impairment, or concurrent major degenerative conditions (including known active cancer) likely to cause functional deterioration. The targeted enrolment was 5–10

participants; the goal was to continue enrolling and testing participants until the RPC processes had been refined sufficiently to adequately meet the program objectives.

General Procedures

Participants underwent a baseline assessment before the RPC and a post-intervention assessment within 1 week after completing the RPC follow-up. Cases were video- or audio-recorded (telephone follow-ups) and were reviewed by members of the research team. Case reviews served two purposes: to train the RC in administering a cognitive strategy-based intervention, and to iteratively review the practicality of the RPC processes. Case reviews were conducted by CD, SM, and JR, and consisted of, at minimum, a debriefing about the case and review of and discussion about the recordings of the consultation. Refinements were made to the RPC process as needed before the next case began.

Data Collection

All participants completed a demographics questionnaire before the intervention. At the post-intervention assessment, the participant completed a semi-structured interview administered by a research assistant who had not been involved in delivering the intervention. The RC kept a log of personal perceptions about each consultation.

RESULTS

Of 9 participants recruited, 7 completed the initial assessment and intervention, and 5 completed the post-intervention research assessment, for an overall withdrawal rate of 44%. Table II describes the 7 participants who completed the initial assessment. The 2 patients who were recruited but who did not participate in the initial assessment experienced changes in their medical status and felt too unwell to participate. Of the two participants who completed the initial assessment but who did not complete the post-intervention

research assessment, one returned to full-time work, and the other experienced a recurrence of the cancer.

Completion of the initial RPC intervention session took approximately 90 minutes for the first 2 cases and less than 45 minutes for the last 2 cases. Completion of the follow-up assessments consistently took 15–20 minutes. Participants set a wide variety of goals related to reducing impairments such as dry mouth, swallowing, or lymphedema; managing psychosocial concerns such as anxiety and not enough time for self; and returning to personally meaningful activities such as eating salad, going to the gym to exercise, or returning to work. The plans developed by the participants included using previously prescribed home exercises, seeking additional services or programs, or developing new individualized self-management strategies.

Table III summarizes the discussion categories from the semi-structured interviews. All completing participants ($n = 5$) found the RPC acceptable and particularly found the goal-setting and planning process to be useful for building confidence in their independent management of their own rehabilitation needs. They reported that the process met a previously unmet need and that issues that had not previously been identified by other team members were addressed.

Ongoing refinements to the RPC throughout the testing resulted in the RPC-beta. Figure 1 presents the beta version of the initial consultation. These were the major changes from the alpha version:

- An alternative process was created for participants who did not have specific, tangible rehabilitation goals. Rather than going through the process of refining goals and planning, a process was established whereby the RC went straight to reviewing the resource Web site. Participants who took this path were given contact information and told how they could contact the RC should they have rehabilitation needs in the future.

TABLE II Description of the study participants

Participant details										
ID	Age (years)	Sex	Cancer type	Treatment	Currently smoking	Comorbidities or medical history	Work status	Financial situation	Living situation	Born in Canada
P01 ^a	62	Female	Hypopharynx	Radiation, chemotherapy	No	NA	Employed part-time	Not enough to make ends meet	With others	Yes
P02	73	Male	Vocal fold cancer <i>in situ</i> (larynx)	Surgery, radiation	No	Benign prostatic hypertrophy	Retired	Some money left over	Alone	Yes
P04 ^a	54	Female	Tonsil (oropharynx)	Radiation, chemotherapy	No	Kidney stones	On disability	Not enough to make ends meet	With others	Yes
P06 ^a	67	Male	Oropharynx	Radiation, chemotherapy	No	NA	Not working outside home	Not enough to make ends meet	With others	Yes
P09	68	Male	Tonsil (oropharynx)	Radiation	Yes	Type 2 diabetes, high blood pressure, rheumatoid arthritis	Retired	Some money left over	With others	No
P08	76	Male	Glottis (larynx)	Radiation	No	High blood pressure	Retired	Just enough to make ends meet	With others	Yes
P12 ^a	63	Male	Oropharynx	Radiation	No	High blood pressure	Working full-time	Some money left over	With others	Yes

^a Had rehabilitation goals.
NA = not applicable.

TABLE III Discussion categories from five post-intervention interviews

Category	Description	Exemplar quotations
Current challenges	All of the participants reported ongoing challenges of varying severities. Most of the challenges were related to symptoms of treatment such as dry mouth, stiff neck, or sore jaw. Fatigue and returning to work full time were also noted as challenges, as was continuing to manage the psychosocial burden of treatment and recovery.	It's difficult with friends and family and acquaintances, etc., because I tend not to try to talk about it.... What comes back is sympathy, and that's not what I'm there for. (P06)
Rehabilitation planning consultation process		
Consultation format	There were mixed preferences for an in-person consultation compared with having access to the consultant over the telephone. A number of participants felt that travel time would be a barrier, because they are not coming to the cancer centre as often any more. However, others preferred the personal connection experienced during the in-person meeting.	—
Goal-setting	Not all participants had rehabilitation goals, but participants who did have such goals found it helpful to have assistance to explicitly form the goals.	[Setting goals] was definitely helpful. (P04)
Planning	Participants developed an action plan and a coping plan in anticipation of barriers and mitigation strategies. Cost, convenience, and time were all identified as barriers when implementing the action plans. Participants noted that the plan needed to be something that could be incorporated into current routines and that they used various strategies to meet their goals—for example, changing the plan from attending a group-based exercise class to returning to their own gym. Participants reported that the planning process gave them more confidence to move forward with their lives.	I wound up just going to the gym on my own, but [the plan] gave me the confidence to go ahead and get active again, which is what I'm doing.... I'm quite happy with my ability to manage on my own ... and [to monitor] my own rehab. (P12) Not only information ... I received some confidence that I was doing it right. It was hard for me to know how far to go, and any programs if I'm exercising, and how much is too much, and how little is too little, and how far do you go, how much do you push, you know. I didn't know if I'm doing the right thing. (P06)
Provision of information and resources	Most participants agreed that, during the consultation, they received information of which they were not previously aware. Several commented on the Web site developed for the process; however, most had not accessed the site on their own, outside of the time with the consultant.	It was informative, you know; it was all very interesting. (P09)
Overall experience	All participants reported a positive experience with the rehabilitation planning consultation. Many indicated that it met an unmet need of identifying rehabilitation-specific issues that are often missed by other members of the medical team. Another recurring theme was that, of the psychosocial support received during the consultation, participants appreciated having someone listen to their concerns and felt supported in dealing with rehabilitation issues.	I think just the fact that there is a process and there is somebody following up ... at Princess Margaret, it was more of a team support during the treatment and then the follow-up after was definitely appreciated and different from my previous experience. (P12)

- Rather than have the BRASH introduced during the initial RPC, survivors received it when they were first recruited, thus providing them with time for contemplation and shortening the face-to-face consultation.
- To increase their engagement in the process, participants were asked to write their own goals and plans during the initial consultation.
- A participant workbook was developed and modified between the first and the last participant. The final version had information about the process, the problem-solving strategy (Goal–Plan–Do–Check), and space to record goals, information received, plans, and any potential barriers and coping plans to be used.
- The orientation segment was lengthened to include discussion about the workbook and a brief introduction to the resource Web site.
- To better capture individual goal performance, a goal measurement tool was developed for use together with the BRASH. That tool was not finalized until the end of the alpha testing period and thus is not included in this report.

DISCUSSION

The RPC aims to help survivors of HN cancer determine their priority rehabilitation needs, set related goals and plans, and implement their plans to meet their goals. To accomplish those objectives, we designed an intervention based in self-management theory that incorporates teaching a global cognitive strategy to survivors, and that aims to increase the self-efficacy of survivors in problem-solving, to build a positive relationship with the RC, and to increase awareness of and access to resources on the part of survivors.

In its refined version, the RPC can be conducted within a feasible timeframe: about 45–75 minutes for the initial consultation, with one 20-minute follow-up. Participants who completed the RPC were positive about the intervention, indicating that it filled a gap in the cancer care continuum, helped them to formulate a rehabilitation plan, and gave them confidence to move forward. The 44% withdrawal rate seems high, but considering the fragility of the population and the fact that we were

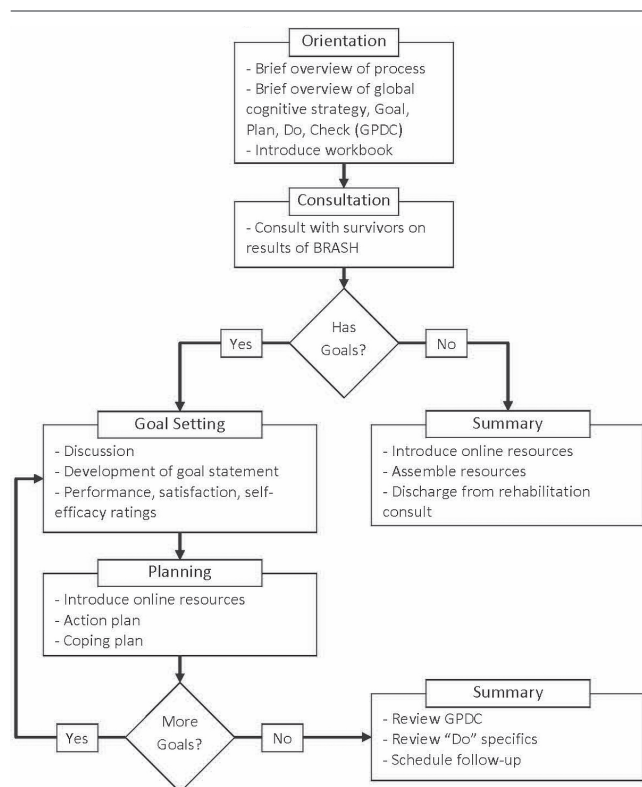


FIGURE 1 Initial rehabilitation planning consultation, beta version. BRASH = Brief Rehabilitation Assessment for Survivors of Head-and-Neck Cancer.

asking them to participate in a development process, that rate is perhaps not surprising. In this first group, 3 of the 4 withdrawals were related to acute illness, which is to be expected in this population.

A pilot test of the refined version of the RPC with a larger sample and a quantitative assessment is currently underway, and a future goal is to conduct a multisite randomized controlled trial. Before that trial, a program for training additional therapists as rcs and a framework for implementation at diverse sites will be developed.

CONCLUSIONS

The RPC was feasible to use within our small sample of survivors of HN cancer. Participants reported success in formulating and implementing rehabilitation plans and increased confidence in moving forward independently. A pilot test of a refined version of the RPC with a larger patient sample is underway.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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