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# A survey of health care professionals and oncology patients at the McGill University Health Centre reveals enthusiasm for establishing a postmortem rapid tissue donation program

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## ABSTRACT

**Background** In the early developmental phase of a postmortem rapid tissue donation (RTD) program for patients with metastatic cancer, we surveyed health care professionals (HCPs) and oncology patients at the McGill University Health Centre (MUHC) to assess their knowledge and attitudes pertaining to RTD from metastatic cancer patients for research purposes.

**Methods** A 23-item survey was developed and distributed to HCPs at tumour board meetings, and a related 26-item survey was developed and distributed to oncology patients at the MUHC Cedars Cancer Centre.

**Results** The survey attracted participation from 73 HCPs, including 37 attending physicians, and 102 oncology patients. Despite the fact that 88% of HCPs rated their knowledge of RTD as none or limited, 42% indicated that they would feel comfortable discussing RTD with their cancer patients. Of the responding HCPs, 67% indicated that their current knowledge of RTD would affect their decision to discuss such a program with patients, which implies the importance of education for HCPs to facilitate enrolment of patients into a RTD program. Of responding patients, 78% indicated that they would not be uncomfortable if their doctor discussed RTD with them, and 61% indicated that they would like it if their doctor were to discuss RTD with them. The HCPs and patients felt that the best time for patients to be approached about consenting to a RTD program would be at the transition to palliative care when no treatment options remain.

**Conclusions** At the MUHC, HCPs and patients are generally enthusiastic about adopting a RTD program for patients with metastatic cancer. Education of HCPs and patients will be an important determinant of the program's success.

**Key Words** Rapid tissue donation, rapid autopsy, warm autopsy

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## INTRODUCTION

Rapid tissue donation (RTD), also known as rapid autopsy, is an organized program for acquiring metastatic tumour tissue for research purposes in a postmortem setting[1]. Rapid tissue donation involves the removal of metastatic tissue within 12 hours of death[2]. Tissues acquired through RTD differ from surgical or biopsy specimens that are often acquired before treatment and come from a single tumour site[3]. The RTD tissue comes from a number of metastatic

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sites and can include normal-tissue control specimens. The tissues can also be matched to samples collected at earlier times in a patient's cancer history.

Given the imperative for the cancer research community to achieve a greater understanding of the mechanisms of therapeutic resistance, interactions between cancer cells and the tumour microenvironment, and intra- or inter-tumour heterogeneity, RTD tissue is of unequivocal value in driving discoveries that will ultimately benefit cancer patients[1].

Previous studies have demonstrated that patients in a U.S. setting generally view RTD favourably[4,5]. As the first stage in an effort to establish a RTD program for patients with metastatic cancer at the McGill University Health Centre (MUHC), we used surveys completed by health care professionals (HCPS) and oncology patients at the MUHC to determine whether those HCPS and patients would be similarly open to participating in such a program. The surveys assessed respondent attitudes, knowledge, and opinions about RTD. Here, we report the findings from the surveys and discuss their relevance for establishing a viable RTD program at our institution.

## METHODS

### HCP Surveys

We conducted hardcopy paper surveys to assess the knowledge and attitudes of HCPS about RTD. Surveys for HCPS were adapted from a similar Moffitt Cancer Centre survey, with that organization's approval[6]. Item generation was performed by the lead and senior authors, and pre-testing was performed with the co-authors. After review and approval of the study by the MUHC research ethics board (no. 2018-3304), copies of the survey (Table I) were distributed to HCPS at tumour board meetings. Before the tumour board session began, the survey was briefly introduced verbally by the lead author of the study, outlining the goals for the survey, as well as the broader initiative to establish a RTD program for research purposes. Hard copies were handed out to all attendees at the session. Using this chunk sampling approach, a representative group of HCPS who work in areas related to oncology were selected[7]. Responses were collected immediately after the tumour board session. All individuals who were given a survey returned a completed version (100% response rate). All HCP surveys were completed between July 2017 and July 2018.

### Patient Surveys

We conducted hardcopy paper surveys to assess the knowledge and attitudes of patients about RTD. Surveys for patients were modified from the HCP survey described in the preceding subsection. Item generation was performed by the lead and senior authors, and pre-testing was performed with the co-authors. After review and approval of the study by the MUHC research ethics board (no. 2018-3304), copies of the survey were distributed to consecutive patients attending the Friday morning oncology clinics of two medical oncologists, before their appointments. The survey was briefly introduced verbally by the lead author of the study in the patient's preferred language (English or French), outlining the goals for the survey, as well as the broader initiative to establish a RTD program for research purposes. Hard copies of the survey (Table II) were given to patients in their language of choice (English or French) to be completed and returned in the waiting room. Using this chunk sampling approach, a representative group of oncology patients was obtained. Of 113 patients approached and asked to complete the survey, 11 refused to participate (1 because of a language barrier, 1 because of acute illness, 9 for unspecified reasons), for a 90% response rate. All patient surveys were completed between September and October 2018.

### Survey Analysis

The Pearson 2-way chi-square test was used in the statistical analyses.

The Consolidated Criteria for Reporting Qualitative Research 32-item checklist for interviews and focus groups is presented in Appendix A, making reference to both the HCP and patient surveys.

## RESULTS

### HCP Survey

Table III shows the characteristics of the 73 HCPS surveyed during tumour board sessions and their attitudes and knowledge pertaining to RTD. The group included attending physicians; trainees such as medical students, residents, and fellows; nurses; and clinical researchers. The most common specialties among the HCPS surveyed were medical oncology, radiation oncology, and surgery. Most participants (69%) had not heard of RTD before completing the survey, and yet 40% indicated that they would feel comfortable discussing RTD with their patients. Having been asked when patients should be approached about possible participation in a RTD program, HCPS most frequently felt that patients should be approached when no treatments were available (30%).

Table IV shows the factors that would affect a decision by a HCP to discuss RTD with a patient. The HCPS indicated that their current RTD knowledge was the most important factor in determining whether they would approach a patient to discuss RTD (84%).

Because attending physicians would be the primary individuals discussing RTD with patients, we investigated the responses of attending physicians as a subgroup. Although 54% of that subgroup indicated that they had never heard of RTD before the survey, 53% responded that they would be willing to discuss RTD with patients. Attending physicians generally viewed their current level of RTD knowledge as being important in determining whether they would discuss RTD with a patient (57%).

### Patient Surveys

Table V shows the characteristics and attitudes of the surveyed oncology patients. The 102 oncology patients who participated were drawn from among the consecutive patients attending the clinics of medical oncologists who routinely see patients with primary breast (76%) or head-and-neck cancers (15%). Those tumour types were chosen specifically because of the contrasting patient participation in research in those disease settings. Breast cancer research

**TABLE I** Rapid tissue donation survey for health care providers

**McGill University Health Centre—Rapid Tissue Donation Survey**[a]

The purpose of this survey is to identify health care professionals' knowledge and attitudes related to consenting patients and their families for postmortem tissue donation. We hope this survey will provide an opportunity for individuals like you to express your opinion and help us to identify the myriad of unique and complex perspectives related to the collection of human biological specimens.

- For each question in this survey, please mark the appropriate box OR type your answer in the space provided.
- Unless the instructions state otherwise, please select only one response in each question.
- Based on certain responses to questions you will be required to skip sections or questions that do not apply.

Thank you for your input.

1 What is your profession?
☐ Attending physician ☐ Medical resident or fellow ☐ nurse or nurse practitioner ☐ Physical therapist ☐ Occupational therapist
☐ Pharmacist ☐ Other (Please specify: _____)

2 What is your specialty or field? (Please check all that apply)
☐ Cardiology ☐ Dermatology ☐ Family medicine ☐ Internal medicine ☐ Molecular medicine ☐ Neurology ☐ Neurosurgery
☐ OB/GYN ☐ Medical oncology ☐ Ophthalmology ☐ Orthopedics ☐ Otolaryngology ☐ Pathology/cell biology ☐ Pediatrics
☐ Pharmacology ☐ Psychiatry ☐ Radiation oncology ☐ Radiology ☐ Surgery ☐ Urology ☐ Other (Please specify: _____)

3 Are you involved in fundamental, translational or clinical research using human tissue samples? ☐ Yes ☐ No

Recent technological advances in genomics and proteomics are making possible a personalized approach to the diagnosis and treatment of cancer. For this personalized approach, repositories of blood and tissue samples combined with patient information are often collected at the time of surgical procedures to understand the mechanisms involved in disease initiation and progression.

4 Do patients ask you about donating their body to science or participating in bio-specimen research studies?
☐ Often ☐ Sometimes ☐ Rarely ☐ Never

5 Prior to this survey, have you ever heard of rapid tissue donation (also known as rapid autopsy)? ☐ Yes ☐ No

Rapid Tissue Donation (RTD) involves the procurement of fresh tissue (within 2–12 hours following the death of a patient). The goals of RTD programs are to obtain high quantity and quality tumour tissue from both the primary tumour and metastasis.

6 Would you feel comfortable discussing RTD with your cancer patients? ☐ Yes ☐ No ☐ Not sure

7 How would you rate your general knowledge of RTD?
☐ No knowledge at all ☐ Limited knowledge ☐ Somewhat knowledgeable ☐ Knowledgeable ☐ Very knowledgeable

8 Have you had any experience with recruiting patients into a RTD program or a similar ethically sensitive procedure?
☐ Yes ☐ No (if no, skip to question 10)

9 Please describe the method of recruitment that has been successful for you in the past when recruiting for RTD or other sensitive procedures:
_____
_____

10 When should you approach patients about possible participation in a RTD program?
☐ At the time of diagnosis ☐ Following first line therapy ☐ Following second line therapy ☐ When there are no treatments available for the patient's disease/stage ☐ Patient should not be approached ☐ Don't Know o Other (Please specify: _____)

11 For each of the following characteristics, please indicate whether your decision to discuss rapid tissue donation would be influenced by:

| No, definitely not | No, probably not | Neutral | Yes, somewhat | Yes, definitely |
|---|---|---|---|---|
| Patient's age | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Patient/patient's family languages spoken | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Patient's current stage of disease | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Lethality of the cancer | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Lethality of cancer in the family | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Perceived religious or cultural concerns based on patient's characteristics | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |

**TABLE I** Continued

| McGill University Health Centre—Rapid Tissue Donation Survey[a] | | | | |
|---|---|---|---|---|
| 11 For each of the following characteristics, please indicate whether your decision to discuss rapid tissue donation would be influenced by: | | | | |
| Personal ethical considerations | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Socioeconomic status of the patient or family | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Your current RTD knowledge | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Your own religious or ethical reasons | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Access to information and patient resources | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| 12 Please describe any personal concerns or recommendation that you have with RTD: _____ _____ | | | | |
| 13 In what year did you graduate from medical school, nursing school etc.? | | | | |
| This is the end of our survey. We sincerely appreciate you taking the time to respond. | | | | |

[a] Adapted from The Moffit Cancer Center Survey, used with permission.

**TABLE II** Rapid tissue donation survey for patients

| McGill University Health Centre—Rapid Tissue Donation Survey |
|---|
| The purpose of this survey is to identify patient knowledge and attitudes related to consenting to postmortem rapid tissue donation (RTD). This survey is NOT requesting your consent for rapid tissue donation. It is simply a preliminary assessment of the feasibility of implementing this procedure at the McGill University Health Centre for patients who do wish to consent. |
| Rapid tissue donation (RTD) is a personal choice whose objective is the postmortem procurement of cancer tissue for research purposes. This process is called "rapid" because it involves the specimen collection from multiple different sites in the body within 2–12 hours following the death of a patient. This is critical in developing our understanding of cancer and will contribute towards research that aims to help future patients with cancer. After the procedure is completed by a pathologist, all organs are returned to the body, besides the tumor tissues used by researchers focused on cancer. The body is returned to the next-of-kin, with an open casket funeral remaining possible in all cases. |
| We hope this survey will provide an opportunity for individuals like you to express your opinion and help us to identify the unique and complex perspectives related to the collection of human biological specimens. |
| For each question in this survey, please mark the appropriate box OR write your answer in the space provided. |
| Unless the instructions state otherwise, please select only one response in each question. |
| Thank you for your input. |
| 1 What is your age? ☐ 18–50 Years ☐ 50–75 Years ☐ >75 Years |
| 2 What is your gender? ☐ Female ☐ Male ☐ Other (Please specify: _____) |
| 3 What is your highest level of education? ☐ High school ☐ CEGEP ☐ Bachelor's degree ☐ Master's degree ☐ Doctorate ☐ Other (Please specify: _____) |
| 4 What is your primary cancer site (site where the cancer started)? ☐ Breast ☐ Lung ☐ Melanoma ☐ Colon ☐ Liver ☐ Pancreas ☐ Stomach ☐ Kidney ☐ Prostate ☐ Bladder ☐ Uterine ☐ Ovarian ☐ Cervical ☐ Thyroid ☐ Sarcoma ☐ Brain ☐ Leukemia ☐ Lymphoma ☐ Other (Please specify: _____) |
| 5 What is the stage of your cancer? ☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ I do not know |
| 6 Have you received chemotherapy for your cancer? ☐ Yes ☐ No ☐ I do not know |
| 7 Have you received radiation treatment for your cancer? ☐ Yes ☐ No ☐ I do not know |
| 8 Have you received surgical treatment for your cancer? ☐ Yes ☐ No ☐ I do not know |

**TABLE II** Continued

**McGill University Health Centre—Rapid Tissue Donation Survey**

9 Have you ever consented to donate cancer tissue (including blood) specifically to research over the course of your cancer?
☐ Yes ☐ No ☐ Not sure

10 Have you ever discussed donating your cancer tissue to research with your doctor? ☐ Yes ☐ No ☐ Not sure

11 Have you ever discussed donating your cancer tissue to research with your family? ☐ Yes ☐ No ☐ Not sure

12 When is the best time for doctors to approach patients about possible participation in a RTD program?
☐ At the time of diagnosis ☐ Following first line therapy ☐ Following second line therapy ☐ When there are no more treatment options available (transition to palliative care) ☐ Patients should not be approached ☐ I do not know ☐ Other (Please specify: _____)

13 Would you feel uncomfortable if your doctor discussed RTD with you? ☐ Yes ☐ No ☐ Not sure

14 Would you like for your doctor to discuss RTD with you? ☐ Yes ☐ No ☐ Not sure

15 Please indicate whether the following would impact your decision to consent to a rapid tissue donation program

| No, definitely not | No, probably not | Neutral | Yes, somewhat | Yes, definitely |
|---|---|---|---|---|
| Your current knowledge of RTD | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| The stage of your cancer | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Having time to think about it and discuss with your family/ next-of-kin | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Your relationship with the doctor asking for your consent to RTD | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Having a conversation about RTD with your doctor to answer your questions | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Having access to an information pamphlet about RTD | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Having the opportunity to learn about the research that will be performed with your donated tissues | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Knowing that your family will receive a hand-written thank you note several weeks after the tissue donation | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Your family / next-of-kin's opinions of RTD | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Your own religious considerations | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Your own non-religious ethical considerations | | | | |
| ☐ | ☐ | ☐ | ☐ | ☐ |

16 Please provide any comments you wish to share about RTD.

_____

_____

is heavily funded and marketed to patients; head-and-neck cancer research is not.

Table VI shows the factors associated with patient interest in RTD. A great proportion of patients would not feel uncomfortable if their doctor discussed RTD with them (77%) and would like their doctor to discuss RTD with them (61%). In agreement with the responses provided by HCPs, patients also felt that the best time for doctors to approach patients to discuss participation in RTD would be the point at which no treatment options remain (34%).

Table VII shows the 2-way chi-square analysis of factors associated with a patient response of discomfort if their doctor

discussed RTD with them and whether they would like their doctor to discuss RTD with them. Patients who had previously received chemotherapy were significantly less likely to be uncomfortable if their doctor discussed RTD with them and were more likely to want their doctor to discuss RTD with them ($p = 0.0342$). Patients with a higher level of education (bachelor degree or higher) were significantly more likely to be uncomfortable if their doctor discussed RTD with them ($p = 0.0265$).

**TABLE III** Characteristics and attitudes of 73 surveyed health care providers

| Variable | Value | |
|---|---|---|
| | *(n)* | (%) |
| Profession | | |
| Attending physician | 37 | 51 |
| Medical resident or fellow | 17 | 23 |
| Nurse or nurse practitioner | 10 | 14 |
| Clinical researcher | 5 | 7 |
| Medical student | 2 | 3 |
| Other | 2 | 3 |
| Specialty or field | | |
| Medical oncology | 18 | 25 |
| Other internal medicine specialty | 3 | 4 |
| Radiation oncology | 9 | 12 |
| Radiology | 9 | 12 |
| General surgery | 7 | 10 |
| Other surgical specialty | 18 | 25 |
| Pathology | 3 | 4 |
| Research | 2 | 23 |
| Other | 4 | 6 |
| Involvement in research using human tissue samples | | |
| Yes | 31 | 43 |
| No | 42 | 58 |
| Year of graduation (latest degree) | | |
| 2010–2018 | 18 | 25 |
| 2000–2009 | 19 | 26 |
| 1990–1999 | 9 | 12 |
| 1980–1989 | 7 | 10 |
| 1970–1979 | 5 | 7 |
| 1960–1969 | 3 | 4 |
| Other | 5 | 7 |
| No response | 7 | 10 |
| Do patients ask you about donating their body to science or participating in biospecimen research studies? | | |
| Often | 1 | 1 |
| Sometimes | 11 | 15 |
| Rarely | 23 | 32 |
| Never | 36 | 49 |
| No response | 2 | 3 |
| Prior to this survey, have you ever heard of rapid tissue donation (also known as rapid autopsy)? | | |
| Yes | 22 | 30 |
| No | 50 | 69 |
| No response | 1 | 1 |
| Would you feel comfortable discussing rapid tissue donation with your cancer patients? | | |
| Yes | 29 | 40 |
| No | 10 | 14 |
| Not sure | 31 | 43 |
| No response | 3 | 4 |
| Self-rated general knowledge of rapid tissue donation | | |
| No knowledge at all | 32 | 44 |
| Limited knowledge | 33 | 45 |
| Somewhat knowledgeable | 5 | 7 |
| Knowledgeable | 3 | 4 |
| Very knowledgeable | 0 | 0 |
| Have you had any experience recruiting patients into a rapid tissue donation program or a similar ethically sensitive procedure? | | |
| Yes | 3 | 4 |
| No | 69 | 95 |
| No response | 1 | 1 |
| When should you approach patients about possible participation in a rapid tissue donation program? | | |
| At the time of diagnosis | 10 | 14 |
| After first-line therapy | 0 | 0 |
| After second-line therapy | 1 | 1 |
| When there are no treatments available for the patient's disease or stage | 22 | 30 |
| Patient should not be approached | 1 | 1 |
| Don't know | 21 | 29 |
| Other | 8 | 11 |
| No response | 10 | 14 |

**TABLE IV** Factors that affect a health care provider's decision to discuss rapid tissue donation (RTD) with a patient

| Factor | Affects decision? | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | No, definitely not | No, probably not | Neutral | Yes, somewhat | Yes, definitely | No response | Combined no | Combined yes | |
| | | | | | | | | *(n)* | (%) |
| Patient's age | 17 | 21 | 12 | 13 | 7 | 3 | 38 | 20 | 35 |
| Languages spoken by patient or patient's family | 16 | 16 | 13 | 16 | 8 | 4 | 32 | 24 | 43 |
| Patient's current stage of the disease | 9 | 10 | 9 | 17 | 25 | 3 | 19 | 42 | 69 |
| Lethality of the cancer | 11 | 9 | 7 | 22 | 21 | 3 | 20 | 43 | 68 |
| Lethality of cancer in the family | 15 | 8 | 21 | 16 | 9 | 4 | 23 | 25 | 52 |
| Perceived religious or cultural concerns based on patient's characteristics | 7 | 10 | 17 | 23 | 13 | 3 | 17 | 36 | 68 |
| Personal ethical considerations | 18 | 10 | 14 | 12 | 16 | 3 | 28 | 28 | 50 |
| Socioeconomic status of the patient or family | 31 | 11 | 20 | 7 | 1 | 3 | 42 | 8 | 16 |
| Current personal knowledge of RTD | 3 | 6 | 14 | 18 | 29 | 3 | 9 | 47 | 84 |
| Your own religious or ethical reasons | 38 | 10 | 17 | 1 | 4 | 3 | 48 | 5 | 9 |
| Access to information and patient resources | 6 | 5 | 21 | 21 | 14 | 6 | 11 | 35 | 76 |

Table VIII shows factors that affect a patient's decision to consent to RTD. Patients most frequently stated that having the opportunity to learn about the research that will be performed with their donated tissue would be important in their decision (72%). That finding again mirrors the responses provided by HCPs, who stated that their knowledge of RTD would be most important in their decision to discuss RTD with patients.

## DISCUSSION

We initiated this study with the intention of developing a greater understanding of the opinions, attitudes, and knowledge about RTD among HCPs and patients at our institution. Previous studies surveyed HCPs and patients about RTD separately[4,6]; our survey is the first to provide HCPs and patients with a similar survey, allowing for comparisons between those two important groups. When comparing responses between HCPs and patients, it became abundantly clear that both groups are not well educated about RTD and that further education will be necessary before engaging in a RTD program. Our results demonstrate that, although HCPs have little knowledge or experience with RTD, many are willing to discuss it with patients. Similarly, patients viewed RTD equally favourably, while sharing many of the same concerns expressed by HCPs.

Based on the fact that many HCPs indicated a desire to learn more about RTD before they would be willing to consent patients, we expect compliance among HCPs to be high after information or education sessions are established to teach HCPs about RTD. An opportunity to learn about RTD is especially important in light of the fact that, when engaged clinicians have meaningful and informed conversation with their patients, consent rates for postmortem organ donation improve[8].

Once a RTD program is established, and HCPs are educated about the program, patients will be educated about RTD through an information pamphlet about the program and through discussion with their medical oncologist. Patients indicated the importance of education about RTD in their survey responses: 68% indicated that having an information pamphlet would be important in their decision to consent to RTD.

Interestingly, although patients who had previously received chemotherapy seemed to be more interested in consenting to a RTD program, other factors (such as disease stage) were not correlated with patient discomfort about RTD or with a desire to have their doctor discuss it with them. Those results suggest that there is likely no way to use patient factors to predict how a patient might respond to a discussion about RTD. Rather, clinicians must use personal judgment based on a patient's attitudes and relationship with them to determine whether the patient is approachable about RTD. Alternatively, consent for RTD can be driven by providing patients with information pamphlets about the program together with a prompt to discuss RTD with their clinician if they are interested. In that way, oncologists need not even be mandated to discuss RTD with patients unless the conversation is initiated by patients themselves.

## CONCLUSIONS

Taken together, our results demonstrate that RTD is viewed favourably by most HCPs and patients, paving the way for implementation of a RTD program at the MUHC.

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**TABLE V** Characteristics and attitudes of 102 surveyed oncology patients

| Variable | Value | |
|---|---|---|
| | *(n)* | (%) |
| Language | | |
| English | 62 | 61 |
| French | 40 | 39 |
| Age | | |
| 18–50 Years | 20 | 20 |
| 50–75 Years | 68 | 67 |
| ≥75 Years | 14 | 14 |
| Sex | | |
| Men | 19 | 19 |
| Women | 83 | 81 |
| Highest level of education | | |
| High school | 31 | 31 |
| CEGEP | 24 | 24 |
| Bachelor degree | 26 | 26 |
| Master degree | 13 | 13 |
| Doctorate | 3 | 3 |
| Other | 4 | 4 |
| No response | 1 | 1 |
| Primary cancer site | | |
| Breast | 77 | 76 |
| Head-and-neck | 15 | 15 |
| Other | 9 | 9 |
| No response | 1 | 1 |
| Current stage | | |
| I | 11 | 11 |
| II | 14 | 14 |
| III | 15 | 15 |
| IV | 28 | 27 |
| I do not know | 27 | 26 |
| Other | 1 | 1 |
| No response | 6 | 6 |
| Previous chemotherapy | | |
| Yes | 72 | 71 |
| No | 27 | 26 |
| I do not know | 2 | 2 |
| No response | 1 | 1 |
| Previous radiotherapy | | |
| Yes | 68 | 67 |
| No | 34 | 33 |
| I do not know | 0 | 0 |
| Previous surgical treatment | | |
| Yes | 69 | 68 |
| No | 31 | 30 |
| I do not know | 0 | 0 |
| No response | 2 | 2 |
| Consented to donate tissue to research in the past | | |
| Yes | 27 | 36 |
| No | 70 | 69 |
| I do not know | 5 | 5 |
| Discussed donating cancer tissue to research with a doctor | | |
| Yes | 8 | 8 |
| No | 92 | 90 |
| I do not know | 2 | 2 |
| Discussed donating cancer tissue to research with family | | |
| Yes | 11 | 11 |
| No | 90 | 88 |
| I do not know | 0 | 0 |
| No response | 1 | 1 |
| When is the best time for doctors to approach patients about possible participation in rapid tissue donation? | | |
| At time of diagnosis | 17 | 17 |
| After first-line therapy | 13 | 13 |
| After second-line therapy | 8 | 8 |
| When there are no treatment options remaining | 34 | 34 |
| I do not know | 21 | 21 |
| Other | 7 | 7 |
| No response | 2 | 2 |
| Would you feel uncomfortable if your doctor discussed rapid tissue donation with you? | | |
| Yes | 15 | 15 |
| No | 79 | 77 |
| I do not know | 8 | 8 |
| Would you like your doctor to discuss rapid tissue donation with you? | | |
| Yes | 62 | 61 |
| No | 16 | 16 |
| I don't know | 24 | 23 |

**TABLE VI** Factors associated with patient interest in rapid tissue donation (RTD)

| Factor | Interested in RTD? | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | No, definitely not | No, probably not | Neutral | Yes, somewhat | Yes, definitely | No response | Combined no | Combined yes | |
| | | | | | | | | *(n)* | (%) |
| Your current RTD knowledge | 27 | 13 | 20 | 14 | 23 | 5 | 40 | 37 | 48 |
| Stage of your cancer | 23 | 12 | 19 | 22 | 23 | 3 | 35 | 45 | 56 |
| Having time to think about it and discuss with family | 25 | 9 | 12 | 25 | 27 | 4 | 34 | 52 | 61 |
| Your relationship with the doctor asking for your consent | 25 | 9 | 15 | 32 | 20 | 1 | 34 | 52 | 61 |
| Having a conversation about RTD with your doctor to answer your questions | 20 | 9 | 10 | 26 | 35 | 2 | 29 | 61 | 68 |
| Having access to an information pamphlet about RTD | 18 | 12 | 13 | 23 | 34 | 2 | 30 | 57 | 66 |
| Having the opportunity to learn about the research that will be performed with your donated tissue | 19 | 7 | 9 | 22 | 44 | 1 | 26 | 66 | 72 |
| Knowing that your family will receive a handwritten thank-you note several weeks after the tissue donation | 28 | 17 | 21 | 15 | 17 | 4 | 45 | 32 | 42 |
| The opinions of your family or next of kin | 30 | 18 | 17 | 15 | 18 | 4 | 48 | 33 | 41 |
| Your own religious considerations | 65 | 12 | 10 | 5 | 8 | 2 | 77 | 13 | 14 |
| Your own nonreligious ethical considerations | 51 | 14 | 15 | 7 | 11 | 4 | 65 | 18 | 22 |

initiating a RTD program and for providing the Moffitt Cancer Centre survey modified for use in the study. We acknowledge Nicholas Meti for help with a subset of patient surveys. Most importantly, we thank the study participants for taking the time to participate.

## 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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**TABLE VII** Factors that affect the patient decision to consent to rapid tissue donation (RTD)

| Factor | Comparator | Yes | No | Total | Sum | *p* Value | Factor | Comparator | Yes | No | Total | Sum | *p* Value |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Factors associated with the response to "Would you feel uncomfortable if your doctor discussed RTD with you?"* | | | | | | | *Factors associated with the response to "Would you like for your doctor to discuss RTD with you?"* | | | | | | |
| Language | English | 8 | 48 | 56 | 0.288671045 | | Language | English | 38 | 9 | 47 | 0.134915978 | |
| | French | 7 | 31 | 38 | | | | French | 24 | 7 | 31 | | |
| | | 15 | 79 | 94 | | | | | 62 | 16 | 78 | | |
| Age | | | | | | | Age | | | | | | |
| | <50 Years | 3 | 13 | 16 | 0.112122687 | | | <50 Years | 12 | 4 | 16 | 0.248569199 | |
| | >50 Years | 12 | 66 | 78 | | | | >50 Years | 50 | 12 | 62 | | |
| | | 15 | 79 | 94 | | | | | 62 | 16 | 78 | | |
| Sex | | | | | | | Sex | | | | | | |
| | Women | 12 | 63 | 75 | 0.000500999 | | | Women | 50 | 13 | 63 | 0.002995392 | |
| | Men | 3 | 16 | 19 | | | | Men | 12 | 3 | 15 | | |
| | | 15 | 79 | 94 | | | | | 62 | 16 | 78 | | |
| Education | | | | | | | Education | | | | | | |
| | ≤CEGEP | 5 | 42 | 47 | 5.258131095 | <0.05 | | ≤CEGEP | 31 | 8 | 39 | 0.143856144 | |
| | ≥Bachelor | 10 | 22 | 32 | | | | ≥Bachelor | 25 | 8 | 33 | | |
| | | 15 | 64 | 79 | | | | | 56 | 16 | 72 | | |
| Primary site | | | | | | | Primary site | | | | | | |
| | Breast | 11 | 59 | 70 | 0.130380117 | | | Breast | 46 | 12 | 58 | 0.063172551 | |
| | Others | 4 | 17 | 21 | | | | Others | 13 | 4 | 17 | | |
| | | 15 | 76 | 91 | | | | | 59 | 16 | 75 | | |
| Stage | | | | | | | Stage | | | | | | |
| | Stage I–III | 6 | 36 | 42 | 0.105544173 | | | Stage I–III | 30 | 7 | 37 | 0.041291291 | |
| | Stage IV | 3 | 23 | 26 | | | | Stage IV | 15 | 3 | 18 | | |
| | | 9 | 59 | 68 | | | | | 45 | 10 | 55 | | |
| Chemotherapy | | | | | | | Chemotherapy | | | | | | |
| | Yes | 8 | 61 | 69 | 4.487157287 | <0.05 | | Yes | 49 | 7 | 56 | 9.365416667 | <0.05 |
| | No | 7 | 16 | 23 | | | | No | 11 | 9 | 20 | | |
| | | 15 | 77 | 92 | | | | | 60 | 16 | 76 | | |
| Radiation | | | | | | | Radiation | | | | | | |
| | Yes | 10 | 51 | 61 | 0.024628941 | | | Yes | 40 | 11 | 51 | 0.100727388 | |
| | No | 5 | 28 | 33 | | | | No | 22 | 5 | 27 | | |
| | | 15 | 79 | 94 | | | | | 62 | 16 | 78 | | |
| Surgery | | | | | | | Surgery | | | | | | |
| | Yes | 11 | 51 | 62 | 0.287952334 | | | Yes | 40 | 14 | 54 | 2.665544332 | |
| | No | 4 | 26 | 30 | | | | No | 20 | 2 | 22 | | |
| | | 15 | 77 | 92 | | | | | 60 | 16 | 76 | | |
| Previous donation | | | | | | | Previous donation | | | | | | |
| | Yes | 6 | 20 | 26 | 1.081730769 | | | Yes | 16 | 4 | 20 | 0.042528736 | |
| | No | 9 | 55 | 64 | | | | No | 42 | 12 | 54 | | |
| | | 15 | 75 | 90 | | | | | 58 | 16 | 74 | | |

**TABLE VIII** Factors that affect the patient's decision to consent to rapid tissue donation (RTD)

| Factor | Affects a decision to consent to RTD? | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | No, definitely not | No, probably not | Neutral | Yes, somewhat | Yes, definitely | No response | Combined no | Combined yes | |
| | | | | | | | | *(n)* | (%) |
| Your current RTD knowledge | 27 | 13 | 20 | 14 | 23 | 5 | 40 | 37 | 48 |
| Stage of your cancer | 23 | 12 | 19 | 22 | 23 | 3 | 35 | 45 | 56 |
| Having time to think about it and discuss with family | 25 | 9 | 12 | 25 | 27 | 4 | 34 | 52 | 61 |
| Your relationship with the doctor asking for your consent | 25 | 9 | 15 | 32 | 20 | 1 | 34 | 52 | 61 |
| Having a conversation about RTD with your doctor to answer your questions | 20 | 9 | 10 | 26 | 35 | 2 | 29 | 61 | 68 |
| Having access to an information pamphlet about RTD | 18 | 12 | 13 | 23 | 34 | 2 | 30 | 57 | 66 |
| Having the opportunity to learn about the research that will be performed with your donated tissue | 19 | 7 | 9 | 22 | 44 | 1 | 26 | 66 | 72 |
| Knowing that your family will receive a handwritten thank-you note several weeks after the tissue donation | 28 | 17 | 21 | 15 | 17 | 4 | 45 | 32 | 42 |
| The opinions of your family or next of kin | 30 | 18 | 17 | 15 | 18 | 4 | 48 | 33 | 41 |
| Your own religious considerations | 65 | 12 | 10 | 5 | 8 | 2 | 77 | 13 | 14 |
| Your own nonreligious ethical considerations | 51 | 14 | 15 | 7 | 11 | 4 | 65 | 18 | 22 |

## APPENDIX A: CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH 32-ITEM CHECKLIST

| | | | |
|---|---|---|---|
| *Domain 1: Research team and reflexivity* | | | |
| Personal characteristics | | | |
| 1 | Interviewer or facilitator | Which author or authors conducted the surveys? | Matthew Dankner |
| 2 | Credentials | What were the researcher's credentials? | Medical student and medical resident |
| 3 | Occupation | What was their occupation at the time of the study? | Medical student and medical resident |
| 4 | Gender | Was the researcher male or female? | Male |
| 5 | Experience and training | What experience or training did the researcher have? | Medical school training, basic ability to interact with patients |
| Relationship with participants | | | |
| 6 | Relationship established | Was a relationship established prior to study commencement? | No |
| 7 | Participant knowledge of the interviewer | What did the participants know about the researcher? | That interviewers were trainees involved in this research project with their medical oncologist |
| 8 | Interviewer characteristics | What characteristics were reported about the interviewer or facilitator? | Both interviewers were white males in the 25-30 demographic |
| *Domain 2: Study design* | | | |
| Theoretical framework | | | |
| 9 | Methodological orientation and theory | What methodological orientation was stated to underpin the study? | |
| 10 | Sampling | How were participants selected? | HCPs: selected on basis of being at tumour board meetings<br>Patients: selected on basis of being patients of Dr. Bouganim or Dr. Asselah and present at the MUHC oncology clinic waiting room |
| 11 | Method of approach | How were participants approached? | HCPs: all attendees at tumour board meetings<br>Patients: selected if they were patients of Dr. Bouganim and Dr. Asselah present at the MUHC Oncology clinic waiting room |
| 12 | Sample size | How many participants were in the study? | 73 HCPs, 102 patients |
| 13 | Nonparticipation | How many people refused to participate or dropped out? Reasons? | HCPs: no refusals<br>Patients: 11 refusals (1 because of language, 1 not feeling up to completing the survey, 9 general refusals) |
| Setting | | | |
| 14 | Setting of data collection | Where were the data collected? | MUHC<br>HCPs: at tumour board meetings<br>Patients: in the waiting room of the Oncology clinic before an appointment with their medical oncologist |
| 15 | Presence of nonparticipants | Was anyone else present besides the participants and researchers? | Patients were frequently accompanied by friends or loved ones |
| 16 | Description of sample | What are the important characteristics of the sample? | HCPs: those present at tumour board meetings, selecting for those with roles in cancer patient care<br>Patients: those who had appointments on the given day at the MUHC Oncology clinic |

## APPENDIX A: CONTINUED

| | | | |
|---|---|---|---|
| *Domain 2: Study design continued* | | | |
| Data collection | | | |
| 17 | Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | HCPs: the survey was introduced by Matthew Dankner as a survey to determine the level of interest of HCPs in bringing a RTD program to the MUHC, and to educate them about it<br>Patients: the survey was introduced as assessing the attitudes and opinions of patients to determine whether a future research program will be initiated at the MUHC that would be similar to organ donation except that it would be specific for cancer patients, whereby they would have the opportunity to donate tissues to research in the event that they pass away from their cancer |
| 18 | Repeat interviews | Were repeat interviews carried out? If yes, how many? | No |
| 19 | Audio or visual recording | Did the research use audio or visual recording to collect the data? | No |
| 20 | Field notes | Were field notes made during and after the interview or focus group? | No |
| 21 | Duration | What was the duration of the interviews or focus group? | Not applicable; took as long as participants needed to complete the survey, typically 5–10 minutes |
| 22 | Data saturation | Was data saturation discussed? | No |
| 23 | Transcripts returned | Were transcripts returned to participants for comment and correction? | No |
| *Domain 3: Analysis and findings* | | | |
| Data analysis | | | |
| 24 | Number of data coders | How many data coders coded the data? | Not applicable; data were pre-coded |
| 25 | Description of the coding tree | Did authors provide a description of the coding tree? | Yes: the entirety of both surveys are provided |
| 26 | Derivation of themes | Were themes identified in advance or derived from the data? | Derived from the data |
| 27 | Software | What software, if applicable, was used to manage the data? | Google Forms (Google Inc., Mountain View, CA, U.S.A.) |
| 28 | Participant checking | Did participants provide feedback on the findings? | No |
| Reporting | | | |
| 29 | Quotations presented | Were participant quotations presented to illustrate the themes or findings? Was each quotation identified? | No |
| 30 | Data and findings consistent | Was there consistency between the data presented and the findings? | Yes |
| 31 | Clarity of major themes | Were major themes clearly presented in the findings? | Yes |
| 32 | Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Yes |

HCP = health care provider; MUHC = McGill University Health Centre; RTD = rapid tissue donation.