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Health Care Providers' Knowledge and Attitudes about Rapid Tissue Donation (RTD): Phase one of Establishing a Rapid Tissue Donation Program in Thoracic Oncology

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Abstract

In preparation for the development of a Rapid Tissue Donation (RTD) program, we surveyed health care providers (HCP) in our institution about knowledge and attitudes related to RTD with lung cancer patients. A 31-item web based survey was developed collecting data on demographics, knowledge and attitudes about RTD. The survey contained 3 items measuring participants' knowledge about RTD, 5 items assessed attitudes about RTD recruitment, and 6 items assessed HCPs' level of agreement with factors influencing decisions to discuss RTD. Response options were presented on a 5-point Likert scale. Ninety-one HCPs participated in the study. 66% indicated they had never heard of RTD prior to the survey, 78% rated knowledge of RTD as none or limited, and 95.6% reported not having ethical or religious concerns about discussing RTD with patients. The majority were either not comfortable (17.8%) or not sure if they felt comfortable discussing RTD with cancer patients (42.2%). 56.1% indicated their knowledge of RTD would play an integral role in their decision to discuss RTD with patients. 71.4% reported concerns with RTD discussion and the emotional state of the patient. Physicians and nurses play an important role in initiating conversations about recruitment and donation to research that can ultimately influence uptake. Increasing HCP knowledge about RTD is a necessary step towards building and RTD program. Our study provides important information about characteristics associated with low levels of knowledge and practice related to RTD where additional education and training may be warranted.

Keywords

Survey; Health Care Providers; Tissue Donation; Oncology; Lung Cancer

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Conflicts of Interest:

The authors have no conflicts of interest to disclose.

INTRODUCTION

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 patient tissue samples combined with clinical data are typically collected at the time of surgery to understand the mechanisms involved in disease initiation and progression. A lesser known collection mechanism is through rapid autopsy or rapid tissue donation (RTD) initiatives where the procurement of ‘fresh’ tissue within 2 to 6 hours following the death of a patient.⁽¹⁾ The goals of RTD programs are to obtain high quantity and quality tumor tissue from both the primary tumor and metastasis. The fresh tissue yielded from rapid collection programs possesses benefits not seen in frozen or paraffin embedded tissue samples.⁽¹⁾ There are several additional benefits from using tissue collected via an RTD initiative. First, because no portion of the tumor tissue needs to remain in the body as it does in biopsies, researchers have access to larger quantities of biospecimens from both primary sites and metastasis and even normal non-involved tissue if deemed necessary. Another benefit is the ability to collect tissues in advanced stages of disease, a time at which traditional biopsies are not performed; this allows for molecular studies of cancers types that are responsible for the majority of lung cancer deaths. The third benefit of RTD is that it allows researchers to establish cell lines from primary and metastatic sites which can be used to study response and resistance to treatment. Lastly, RTD research allows for the study of heterogeneity of tumor types, and the formation, response, and resistance to drugs. RTD research can link metastases to the primary cancer as the high-quality tissue may retain characteristics that are lost with frozen material.

While the use of rapid tissue collection offers many opportunities to increase the understanding of biological processes involved in cancer, and the development of new therapies for cancer patients, there are ethical concerns from both the patient and health care provider perspective. The Moffitt Cancer Center recently embarked on a project to develop a RTD program to obtain lung tissue and metastatic tumor from patients. In preparation for the development of this RTD program, we surveyed health care providers (HCP) in our institution about their knowledge and attitudes related to consenting patients for a RTD program. In this manuscript we report on the findings of this survey and offer discussion on the need to address ethical concerns among providers before initiating these programs.

STUDY POPULATION AND METHODS

In this study we used a web-based survey to assess knowledge and attitudes related to a RTD program among HCPs in our institution. After obtaining a waiver of informed consent from the University of South Florida Institutional Review Board, we developed a 31-item survey which collected data on demographics, information on training and career, and knowledge and attitudes about a RTD program. The survey was created in a web-based format by Moffitt’s Survey Methods Core and was only available on Moffitt’s intranet. All Medical Doctors, Physicians Assistants, and Advanced Registered Nurse Practice were invited to take the survey anonymously via an inter-office email invitation. The web survey was available for 3 months between March and April 2012.

In the survey we provided the following definition of RTD: “Rapid tissue donation (RTD) involves the procurement of ‘fresh’ tissue within 2 to 6 hours following the death of a patient. The goals of rapid tissue donation programs are to obtain high quantity and quality tumor tissue from both the primary tumor and metastasis.” The survey contained 3 items to measure participants’ knowledge about RTD (e.g. “rate your general knowledge of RTD”); 5 items assessed attitudes that may serve as barriers to RTD recruitment (e.g. “ethical or religious concerns”); 6 items assessed HCPs’ level of agreement about factors that may

influence decision to discuss RTD (e.g. “would your decision to discuss RTD be influenced by the lethality of the cancer?”). Response options were presented on a 5-point Likert scale ranging from “no, definitely not” to “yes, definitely.” The data are reported as N-values and frequencies.

RESULTS

Among the 222 HCPs at Moffitt, 91 completed the survey yielding a 24% response rate which is comparable to those observed in other national surveys of physicians in the United States.(2, 3) Demographic characteristics of the HCPs are provided in Table 1. There were slightly more males than females (53.8% vs. 46.1%) while Whites (71.4%) non-Hispanic/Latino (90.1%) were the most frequent racial/ethnic groups. Catholics were the most prevalent religious group (41.8%), but nearly 40% report ‘other’ and 80% reported they are currently married or living with someone. Approximately half of the study population attained their medical degree/health care degree after the year 2000 (49.5%), and 60.4% possess a medical degree (MD).

HCPs practice characteristics are presented in Table 2. Nearly 62% of the HCPs reported seeing 21 patients per week. Furthermore, the majority of the study population reported being involved in clinical research (71.4%) and using human biological samples for their research (76.6%). However, 69.2% indicated that they do not discuss organ donation with patients and conversely, 29.7% indicated patients have asked them about organ donation. The majority of the sample (93.4%) has never had experience recruiting patients for an ethically sensitive program.

Table 3 presents the self-reported knowledge and attitudes. Approximately 66% of HCPs indicated they had never heard of RTD prior to the survey, 78% rated their knowledge of RTD as none or limited, and 95.6% reported not having personal ethical or religious concerns about discussing RTD with a patient. However, a majority of the sample were either not comfortable (17.8%) or not sure if they feel comfortable discussing RTD with a cancer patient (42.2%). In terms of timing for the discussion, 58.2% did not feel comfortable discussing RTD with a patient during an initial appointment; however, 56.1% of HCPs indicated their current knowledge of the topic plays an integral role on their decision to discuss RTD with a patient. The number one worry HCPs had (71.4%) about RTD discussion with a patient was the emotional state of the patient and the most cited benefits about RTD were heterogeneity (sampling of multiple tumor sites, 25.3%) and the ability to reveal newer therapies (25.3%). Interestingly, only 11% of the sample selected “testing on later stage or aggressive cancers” as a benefit to RTD.

Factors that may influence discussing RTD are presented in Table 4. Lethality of the cancer (31.9%) and patient’s current stage of the disease (29.7) were the most influential factors in our study population while patient’s age (25.3%) and socioeconomic status (42.9%) were the least influential factors

DISCUSSION

In this survey that assessed the knowledge and attitudes related to RTD among HCPs from a tertiary Comprehensive Cancer Center, we report that overall knowledge of RTD appears low but there was support for such initiative. This is among the first studies to examine knowledge and attitudes of RTD among HCPs. It is well recognized that physicians and nurses play an important role in initiating conversations about organ procurement and that can ultimately influence the rate of accrual.(4, 5) The development of a strong HCP-patient relationship, based upon mutual respect and trust, with open lines of communication

between all parties is crucial for the successful implementation and sustainment of an RTD program.

Many of the studies conducted to date on organ procurement have been in the context of organ donation programs for the purposes of transplantation. There are far fewer studies that have focused on tissue procurement for clinical research through RTD protocols. The long-standing history of organ donation programs for transplantation has helped lay the ground work and ethical framework for procurement of tissue for research. This type of relationship, which leads to an increased consent rate,(4, 5) becomes even more important in the context of a life threatening or terminal disease. The presence of a strong relationship between the health care team and the patient encourages open discussion about complex subject matter. Approaching end-of-life communications can be difficult because discussions need to be approached with sensitivity and often patient preferences about end of life care are ambivalent.(6) Prior evidence indicates that the knowledge, attitudes and skills for physicians and nurses to initiate and conduct effective end-of-life communication varies widely and can ultimately affect decision-making.(4) Pentz et al recognize that participating in RTD programs may generate feelings of distress, fear, anxiety and objection for health care professionals as well as patients.(7) Less is know about specific health care professionals' attitudes towards recruiting patients and families for post-mortem donation programs. From the limited published data available on establishing institutional RTD programs, not one reported on the attitudes of staff. Several of these studies did report on patient and family barriers and facilitators to these programs. The most commonly reported barriers were: distressed relatives who did not wish to support patients RTD consent;(8) the drain on institutional staff time to consent and retrieve the tissue; and the inability to recruit sufficient numbers of patients to create a viable program/database. Institutions with RTD programs reported obtaining the best results when relying on experts and partnering with patient family groups;(1, 9) and working with hospice.(10) Physicians and nurses have been identified as the gate keepers in organ donation programs;(11) therefore, gaining a better understanding of how their roles influence acceptance rates has been the focus of many organ donation studies.⁸

Understanding HCP perceptions of their roles in research and ethics may aid in defining the concept of beneficence and its associated problems in RTD programs. HCP who view themselves as causing psychological harm to a patient or family by introducing RTD opportunities may not feel this is justified, even if the resulting knowledge will benefit humanity. As Levine previously reported (12), there is no evidence supporting the best course of action in these situations, however it is agreed that a discussion of potential ethics problems should occur.

This survey was implemented because our ultimate goal is to initiate and sustain an RTD program for lung cancer patients in Moffitt Cancer Center's Thoracic Oncology Program. Lung cancer is the leading cause of cancer-related death among both men and women in the US. The 5-year survival rate for early stage non-small cell lung cancer (NSCLC) is ~50% but the survival rate decreases precipitously to 4%"(13) among patients with late stage disease underscoring the need to identify target therapies that classifying patients to tailored patient-specific therapy. Although targeted agents are becoming more common in the treatment of lung cancer, they have limited success and are not available to all lung tumors because of their targeted mechanism of treatment. Access to tissues from patients treated with targeted agents via a RTD program may also allow researchers to reveal why the agents were not successful, why tumors developed resistance to the agent, and if new targetable genetic alterations occurred. Furthermore, RTD tissues from patients that were treated with standard-of-care agents are valuable because they may reveal targetable genetic alterations that could lead to new and improved therapies.

While this study represents an important first step in understanding baseline levels of knowledge among HCPs, there are certain limitations that must be considered. Our sample was recruited from a single tertiary Comprehensive Cancer Center and the majority of the respondents were self-reported Caucasians with few HCPs self-identifying as Black or African American or Hispanic or Latino. Thus, because of the nature of this institution and demographics of our respondents, the findings from this survey may not be generalizable and representative of HCPs from other institutions. Additionally, our sample size of 91 participants is somewhat modest in size and limits our ability to analyze subgroups in the analysis. However, because RTD programs are rather rare, there is no reason to believe the knowledge of RTD programs will differ from other institutions. Moreover, there is no reason to believe that the attitudes of our diverse HCPs at Moffitt would differ from other institutions as well. Another possible limitation is that the survey stated tissues collected via RTD would be “high quantity and quality tumor tissue” and it never explicitly stated that the RTD program was intended for research purposes. Thus, there is the potential misunderstanding of the intent of a RTD. Given these limitations future studies is warranted in additional institutions to replicate and validate the findings presented in this paper.

There are several institutions that have established RTD Programs in the US. As the benefits of Rapid Autopsy Programs become clearer and additional programs are developed, it is crucial that we learn from institutions like the University of Michigan,(14) Duke University, (15) Washington University,(9) and Johns Hopkins.(16) These institutions report that the decision to participate is based upon a strong patient-physician relationship and on the clinical assessment of the patient’s emotional state.(16) Literature recognizes the complexity of these programs and success is contingent upon infrastructure, time commitment and buy-in from all physicians involved.(10) The results of this survey suggested more training is needed for health care providers to learn about RTD prior to the initiation of a research program. There are currently no RTD trainings that exist for biomedical researchers that are infused with the perspective of patients and healthcare providers. Our study provides important preliminary information about knowledge and attitudes related to RTD where additional research and education may be warranted.

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Table 1

Health Care Providers' Demographic Characteristics (N = 91)

Demographic Characteristic	N	%
Gender		
Male	49	(53.8)
Female	42	(46.1)
Missing/Unknown/No response	0	(0.0)
Race		
Asian	10	(11.0)
Black or African American	3	(3.3)
White	65	(71.4)
Other	8	(8.8)
Missing/Unknown/No response	5	(5.5)
Ethnicity		
Hispanic or Latino	7	(7.7)
Not Hispanic or Latino	82	(90.1)
Missing/Unknown/No response	2	(2.2)
Religious Background		
Catholic	38	(41.8)
Protestant	12	(13.2)
Jewish	5	(5.5)
Other	36	(39.6)
Missing/Unknown/No response	0	(0.0)
Relationship Status		
Currently married/living with someone	73	(80.2)
Single/never married	11	(12.1)
Separated/divorced/widowed	4	(4.4)
Missing/Unknown/No response	3	(3.3)
Year Medical/health care degree obtained		
1999 or earlier	46	(50.5)
2000 or later	45	(49.5)
Missing/Unknown/No response	0	(0.0)
Current degree or title		
M.D.	55	(60.4)
ARNP/PA/CRNA	29	(31.9)
Ph.D.	2	(2.2)
D.O.	1	(1.1)
Missing/Unknown/No response	4	(4.4)

Table 2

Health Care Providers' Practice Characteristics

Characteristic	N	%
Number of Patients Seen Per Week		
20 or fewer	34	(37.4)
21 or more	56	(61.5)
Missing/Unknown/No response	1	(1.1)
Involved in Clinical Research		
Yes	65	(71.4)
No	26	(28.6)
Missing/Unknown/No response	0	(0.0)
Use of human biological samples for research		
Yes	49	(53.8)
No	15	(16.5)
Missing/Unknown/No response	27	(29.7)
Discussed organ donation with patients		
Yes	28	(30.8)
No	63	(69.2)
Missing/Unknown/No response	0	(0.0)
Do patients asked you about organ donation		
Yes	27	(29.7)
No	64	(70.3)
Missing/Unknown/No response	0	(0.0)
Experience recruiting patients for ethically sensitive procedure or program		
Yes	6	(6.6)
No	85	(93.4)
Missing/Unknown/No response	0	(0.0)

Table 3

Health Care Providers' Knowledge and Attitude about RTD

Knowledge and Attitude	N	%
Prior to survey, have you heard of RTD		
Yes	31	(34.1)
No	60	(65.9)
Missing/Unknown/No response	0	(0.0)
Rate your general knowledge of RTD		
None/limited	71	(78.0)
Somewhat/knowledgeable	20	(22.0)
Missing/Unknown/No response	0	(0.0)
Ethical or religious concerns about discussing RTD with a patient		
Yes	4	(4.4)
No	87	(95.6)
Missing/Unknown/No response	0	(0.0)
Comfortable discussing RTD with cancer patients		
Yes	36	(40.0)
No	16	(17.8)
Not sure	38	(42.2)
Missing/Unknown/No response	1	
Comfortable discussing RTD with a patient you are seeing for the first time		
Yes	8	(8.8)
No	53	(58.2)
Not sure	30	(32.9)
Missing/Unknown/No response	0	(0.0)
Is your decision to discuss RTD with a patient influenced by your current knowledge of the topic		
Yes	51	(56.0)
No	15	(16.5)
Not sure	24	(26.4)
Missing/Unknown/No response	1	(1.1)
Worries about RTD		
Emotional state of the patient following introduction of this topic	65	(71.4)
Ethical and legal issues related to informed consent	6	(6.6)
Ethical and legal issues related to the storage of human biological samples of deceased individuals	2	(2.2)
That the technologies can easily be used for the wrong purposes	3	(3.3)
Missing/Unknown/No response	15	(16.5)
Benefits about RTD		
Provides larger tumor samples	13	(14.3)
Allows sampling of multiple tumor sites (heterogeneity)	23	(25.3)
Allows testing on later stage or aggressive cancers (Stage III–IV)	10	(11.0)
Ability to reveal or confirm newer therapies/methods	23	(25.3)
Obtaining fresh tissue	15	(16.5)

Knowledge and Attitude	N	%
Missing/Unknown/No response	7	(7.7)

Table 4

Impact of patient factors on the discussion of RTD (n, %)

Would your decision to discuss RTD be influenced by...?	No, definitely not		No, probably not		neutral		Yes, somewhat		Yes, definitely		Missing/Unknown/No response	
	N	%	N	%	N	%	N	%	N	%	N	%
The patient's age	23	(25.3)	28	(30.8)	16	(17.6)	19	(20.9)	4	(4.4)	1	(1.1)
Patient's current stage of the disease	6	(6.6)	10	(11.0)	9	(9.9)	37	(40.7)	27	(29.7)	2	(2.2)
Lethality of the cancer	8	(8.8)	13	(14.3)	12	(13.2)	28	(30.8)	29	(31.9)	1	(1.1)
Perceived religious or cultural concerns based on patient's characteristics	5	(5.5)	15	(16.5)	19	(20.9)	34	(37.4)	17	(18.7)	1	(1.1)
Socioeconomic status of the patient	39	(42.9)	23	(25.3)	18	(19.8)	8	(8.8)	1	(1.1)	2	(2.2)
Access to information and patient resources	6	(6.6)	7	(7.7)	19	(20.9)	40	(44.0)	18	(19.8)	1	(1.1)