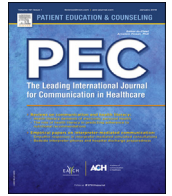




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# Patient, caregiver and physician perspectives on participating in a thoracic rapid tissue donation program

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### ABSTRACT

**Objective:** The collection of posthumous tissue from advanced stage lung cancer patients is beneficial to medical science. Recruiting living patients to a Rapid Tissue Donation Program (RTD) poses several psychosocial challenges and little is known about perceptions of joining this type of program. This study qualitatively examined perceptions of advanced stage lung cancer patients (n = 14) participating in a lung cancer RTD program, their NoK (n = 11), and physicians (n = 6) at the Thoracic Oncology Clinic at H. Lee Moffitt Cancer Center & Research Institute, Tampa, Florida USA.

**Methods:** Semi-structured interviews were conducted with participants and interview transcripts were analyzed using the constant comparison method.

**Results:** Majority of patients joined to give back to research, discussed participation with family members, and desired for family to receive information about the use of the tissue after their death. All participating NoK were supportive of their family member's decision. Physicians described the program as running smoothly, but provided suggestions for process improvements.

**Conclusion:** Participants joined with intention to give back to research community and families were supportive of loved one's participation in RTD. Physicians agreed with overall process.

**Practice implications:** Key factors for a successful RTD program is tailoring to institutional and individual needs.

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## 1. Introduction

Precision medicine is an important tool in the treatment of cancer, particularly lung cancer [1]. Precision medicine relies on results of blood analyses and tissue samples, merged with personal clinical information to determine factors associated with treatment response and clinical outcomes [2]. In the treatment of cancer, a major challenge in the application of precision medicine is the limited amount of tissue available from patients with

advanced disease and refractory disease. Rapid tissue donation (RTD), also known as rapid autopsy, warm autopsy, or posthumous tissue donation, is the procurement of 'fresh' tissue (primary tumor and metastases) within 24–48 h after death of a cancer patient. These tissues provide an opportunity for genomic and proteomic research to improve understanding of: drug resistance, especially in the context of targeted therapy and immune therapy [3]; heterogeneity of advanced cancer, including differences between primary tumor and metastatic lesions [4] and; refractory cancers [3].

Publications on posthumous tissue collection programs are increasing in popularity [5,6], but to our knowledge, none have discussed the donors perceptions about participating in such programs. Improved understanding of their perceptions could lead

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to greater gains in knowledge, increase enrollment of patients, allow more centers to create RTD programs, and potentially allow consortia of RTD centers. While there are benefits to medical science with the collection of posthumous tissue, recruiting living cancer patients to participate poses several challenges [7], as has been shown in other rapid autopsy programs. A warm autopsy program for idiopathic pulmonary fibrosis identified critical areas to focus on in program development, namely: listening to the patient; ensuring the decision is based on free choice; and involving the family early in the discussions [7]. Another rapid autopsy program for Alzheimer's research and brain tissue also identified the need to involve the family, but suggested the use of nurse clinicians to participate in the research and maintain close contact with patient donors [8]. However, formative research at our institution indicated patients preferred to work directly with their physician, while nurses were not comfortable being involved in RTD discussions [9]. Discomfort from the healthcare team is not uncommon as some staff may be uncomfortable broaching the topic feeling it sends a negative message to the patient [10,11].

Additionally, while program participation may be desired by the patient, family and loved ones may be unwilling due to the logistics or personal beliefs about tissue donation [5]. If next of kin (NoK) disagree with the patient's decision, there may be a legal obstacle to following the patient's wishes since NoK "own the body" post death [12,13]. For the purpose of this study, NoK was used when referring to patients' family members, companions, and loved ones.

Our previous formative research examining patients, their loved ones, hospice members, pathologists, funeral homes, and health care provider's perceptions of a hypothetical RTD program found strong support [9,11]. Additionally, feedback from these sources was used to develop educational materials, talking points for physicians as well as a detailed process for program implementation [9].

This study examined the patient's perceptions regarding participation as well as the psychosocial and procedural concerns

of patients who consented to the lung cancer RTD program at H. Lee Moffitt Cancer Center & Research Institute, their NoK, and the physicians who discussed it with them. Our goal was to use these data in real time by immediately changing any aspect of the recruitment or consent process with which patients, NoK, or their physicians had a concern.

## 2. Methods

Fig. 1 describes the logistical steps of the RTD process. The study received approval from Chesapeake IRB (Columbia, MD) and a waiver of written informed consent was granted.

### 2.1. Sample

Participants and physicians were recruited at the Thoracic Oncology Clinic at H. Lee Moffitt Cancer Center & Research Institute, Tampa, Florida.

### 2.2. Patient and NOK interviews

From September 2015 to January 2016, nineteen lung cancer patients were recruited to participate in the RTD program. The average age at enrollment was 66 years, 53% (n = 10) were female, 68% (n = 13), 100% (n = 19) were white, had adenocarcinoma, 21% (n = 4) small cell lung cancer, and 11% (n = 2) squamous cell carcinoma. The majority, 84% (n = 16), were former smokers (Table 1). Two patients declined to participate in RTD and also declined the interview.

A total of 25 participants, patients (n = 14) and NoK (n = 11), were interviewed. Demographic data for NoK were not collected. Three RTD participants declined the interview and two participants died before they could be interviewed (Table 1). The majority of interviews occurred within one week of the RTD discussion and three occurred within four weeks. These interviews lasted between 10 and 60 min.

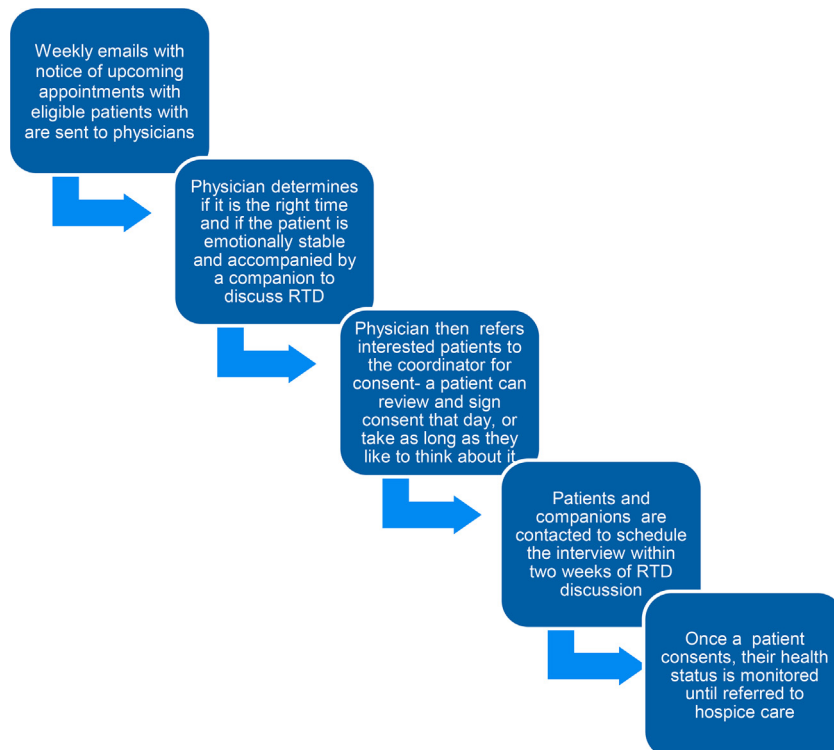


Fig. 1. RTD Process.

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