Melanoma Survivors: Health Behaviors, Surveillance, Psychosocial Factors, and Family Concerns

Pilot Study

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Background

• Cancer survivorship cohorts are growing

• 1971 → 3 million cancer survivors in US

• 2001 → 9.8 million cancer survivors in US
  – Cancer survivors represent 3.5% of the US population

Background

• Cancer survivorship cohorts are growing due to:
  – Early detection via screening efforts
  – Secondary prevention efforts
  – Advanced treatment modalities
  – Decreased mortality from other causes
Background

• Cancer survivorship research focuses on:
  – Identification of and interventions for long term and late effects
  – Optimal follow-up and surveillance
  – Methods of optimizing health after cancer
  – Models of follow-up care
Background

- Melanoma represents 6% of primary cancers among cancer survivors
- Melanoma survivors are an understudied group
- There are an estimated 629,822 melanoma survivors based on recent SEER data
- Little is known about melanoma survivors
Main Objectives

• Establish a cohort of melanoma survivors

• Describe current behaviors related to surveillance and screening practices, health behaviors, psychosocial and cognitive factors, and family concerns in melanoma survivors
Specific Objectives

1. Identify and recruit melanoma survivors to establish a survivorship cohort
2. Conduct focus groups (n=88)
3. Develop survey
4. Identify and recruit melanoma survivors (n=300) and conduct a pilot survey study
Specific Aim 1

1. Identify and recruit melanoma survivors to establish a focus group cohort
2. Conduct focus groups
3. Develop survey
4. Identify and recruit melanoma survivors (n=300) and conduct a pilot survey study
Specific Aim 1 - Methods

DMT DATABASE
MSKCC OUTPATIENT CLINICS

• Identify patients by age, gender, stage, years since diagnosis, and other key variables
Specific Aim 1 - Methods

DMT DATABASE
MSKCC OUTPATIENT CLINICS

• Recruit patients by telephone, letter invitation and/or personal invitation
Specific Aim 1 - Methods

DMT DATABASE

- 8,359 Melanoma patients based on DMT database (1992-2005)

<table>
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<th>Stage Type</th>
<th>Count</th>
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<td>Stage 4</td>
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Specific Aim 2

1. Identify and recruit melanoma survivors (n=88) to establish a focus group cohort
2. Conduct focus groups
3. Develop survey
4. Identify and recruit melanoma survivors (n=300) and conduct a pilot survey study
Specific Aim 2 - Methods

- Conduct 8 groups
- Recruit 11 participants/group
- Total of 88 patients recruited/informed consent
- Expect 80% participation rate
Specific Aim 2 - Methods

- Trained moderator leads group
- Audio-taped discussion/2 hours
- $50 stipend to participants
Eligible melanoma survivors recruited
(n = 88)

< 50 years old
(n = 44)

1 - < 5 years since diagnosis
(n = 22)
Focus Group Type A
(n = 11)
Focus Group Type B
(n = 11)

5 - 10 years since diagnosis
(n = 22)
Focus Group Type A
(n = 11)
Focus Group Type B
(n = 11)

≥ 50 years old
(n = 44)

1 - < 5 years since diagnosis
(n = 22)
Focus Group Type A
(n = 11)
Focus Group Type B
(n = 11)

5 - 10 years since diagnosis
(n = 22)
Focus Group Type A
(n = 11)
Focus Group Type B
(n = 11)
Specific Aim 2 - Methods

FOCUS GROUP TYPE A

• Impact of melanoma on patient health behaviors, lifestyle and quality of life
• Practices related to physician screening, self-screening, and other ongoing follow-up care
• Anxieties post-treatment, including concerns about melanoma recurrence
• Patient concerns for family members, including their risk for developing melanoma
Specific Aim 2 - Methods

FOCUS GROUP TYPE B

- Impact of melanoma on patient health behaviors, lifestyle and quality of life
- Practices related to physician screening, self-screening, and other ongoing follow-up care
- Anxieties post-treatment, including concerns about melanoma recurrence
- Economic issues arising from diagnosis and treatment
Specific Aim 3

1. Identify and recruit melanoma survivors (n=88) to establish a focus group cohort
2. Conduct focus groups
3. Develop survey
4. Identify and recruit melanoma survivors (n=300) and conduct a pilot survey study
Specific Aim 3 - Methods

- Develop survey based on:
  - Existing research/available data collection tools
  - Qualitative text analysis of focus group discussions
  - Computer-assisted qualitative data analysis (Atlas/ti)
Specific Aim 3 - Methods

- Survey to include:
  - Demographics
  - Sun sensitivity
  - Eye and hair color
  - Color of untanned skin
  - Sun exposure
  - Skin self-examination
  - Sun protection practices and frequency of sunburns
  - Psychosocial/cognitive factors
    - Skin cancer knowledge
    - Skin awareness
    - Cancer worry
    - Perceived risk of recurrence
    - Cancer risk and screening behaviors
    - Access to health care and insurance
Specific Aim 4

1. Identify and recruit melanoma survivors (n=88) to establish a focus group cohort
2. Conduct focus groups
3. Develop survey
4. Identify and recruit melanoma survivors (n=300) and conduct a pilot survey study
Specific Aim 4 - Methods

DMT DATABASE
MSKCC OUTPATIENT CLINICS

- Identify a sample of patients by age, gender, stage, years since diagnosis, and other key variables
Specific Aim 4 - Methods

**DMT DATABASE**
**MSKCC OUTPATIENT CLINICS**

- Recruit patients (n=300) by telephone, letter invitation and/or personal invitation
Specific Aim 4 - Methods

**CONDUCT SURVEY**

- Pilot survey melanoma survivors (n=300)
- $25 stipend to participants
- Obtain preliminary data
- Determine feasibility of larger scale study
Summary

Identify and recruit melanoma survivors → Conduct focus groups → Develop survey instruments → Identify, recruit, and conduct survey study
Summary

• Establish a cohort of melanoma survivors

• Describe current behaviors related to surveillance and screening practices, health behaviors, psychosocial and cognitive factors, and family concerns in melanoma survivors

• Optimize health in cohort of melanoma survivors
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