

Patients' Perspectives Risks and Benefits of Radiation Exposure from Medical Diagnostics

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Patients' Perspectives

- How much do patients ask? What do we want to know? What do we want to understand regarding radiation exposure
- How may knowing more affect our decision to have a test?
- What are patient concerns about tracking exposures
- What kind of studies and/or evidence would we like to see in this domain?
- What is patient protection in medical exposure?
- Looking forward—conclusions and recommendations

How much do patients ask? What do we want to know? What do we want to understand regarding radiation exposure

- Framing the questions
 - In order to ask a question, need to know there is a question to ask
 - Different values and perspectives depending on diagnosis—advanced cancer, in remission, “cured”

How much do patients ask? What do we want to know? What do we want to understand regarding radiation exposure

- Who's having the discussion?
 - Very little discussion between patients and health care providers of risks and benefits
 - Not a common focus of patient advocacy
 - Rarely brought up by patients

How much do patients ask? What do we want to know? What do we want to understand regarding radiation exposure

- Dialogue for understanding
 - In absence of risk/benefit discussion between patient and health care provider, strong bias to want more procedures/tests
 - Critical to understand previous exposure to radiation and potential harms from past, present and future exposure
 - Forthright discussion of need for test, what knowledge will be gained from test and how knowledge will be used to benefit patient

How may knowing more affect our decision to have a test?

- Anxiety about current condition often drives desire for more testing
- With knowledge, we can make decisions that align with our values and approach to our health care

What are patient concerns about tracking exposures?

- Not being able to get the tests we perceive we need
- Seeing multiple doctors, having repeat tests with no method of tracking procedures and their effects
- Privacy—a small, but always important, concern for survivors

What kind of studies and/or evidence would we like to see in this domain?

- Impact of medical radiation on long-term health of cancer survivors
- What are safe levels of radiation
- Retrospective studies looking at what tests have been conducted and what answers they provided

What kind of studies and/or evidence would we like to see in this domain?

- Guidelines for strict quality assurance standards for radiation emitting devices
- More research on use/improvement of alternative, safer technologies
- Developing validated decision making tools

What is patient protection in medical exposure?

- Information to make informed decisions
- Testing when evidence supports benefits to patients
- More conservative use of frequent testing

What is patient protection in medical exposure?

- Effective monitoring of exposure to radiation
- Personal exposure cards that travel with the patient as she goes through the medical system

Looking forward—conclusions and recommendations

- Take the long view into account in decision making. Learn from approach to making treatment decisions with a view to impact on survivorship/quality of life
- Include tools for decision making about radiation exposure in survivorship plans

Looking forward—conclusions and recommendations

- Regularly include discussion of need when doctors are ordering diagnostic tests
- Work with patient advocacy groups to build awareness and increase patients' and health care providers' knowledge of risks/benefits of radiation exposure to enable informed decision making