CANCER SCIENCE FOR CANCER ADVOCATES: REPORT OF A PILOT PROGRAM

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Background.

• Kenyan Network of Cancer Organizations (KENCO) is the national umbrella body of cancer civil society with over 25 member organizations.

• KENCO recognizes that advocates play an important role as cultural brokers and agents of change as new oncology frontiers evolve.

• Member organizations work in diverse fields, including advocacy, patient support, screening and influencing policy.

• Members make direct request for capacity building in cancer science to enable them confidently engage the public, policy makers and media with evidence based information.
Justification.

- The cancer control agenda in Kenya has largely been kept in the public domain by lay advocates, cancer survivors and care givers who do not have any form of training in the fundamentals of cancer science.

- Advocates bring unique viewpoints to the cancer control agenda ensuring that scientific interventions are people focused.

- Advocates can be called upon to serve on advisory boards such as ethics and technical committees representing the public.

- Advocates are best positioned to articulate the impact of the cancer on the daily lives of ordinary citizens.

Anderson & McCleary (2015)
Pilot Project Goals.

• Develop a critical mass of survivors and advocates with sound scientific knowledge.

• Increase appreciation of the value of collaboration with the scientific community to support, influence and strengthen cancer control.

• Broaden advocates’ understanding of cancer by exposing them to the scientific foundations of cancer control.
Methodology I

• A pilot training program was designed based on learning needs as reported by the cancer advocates.

• The curriculum was based on what would add value to advocacy work when engaging the public, media, and policy makers.

• The course focuses on basics of cancer biology, epidemiology, cancer treatment, terms used in oncology as well as communication skills.
Methodology II

• A faculty of nurses working in oncology from public and private hospitals prepared the content and delivered the program by breaking down complex scientific concepts to an easy to understand format.

• Organizations were asked to nominate one participant who is involved in cancer awareness.

• The program was taught using a combination of didactic lectures, group work and experiential sharing.

• Participants were then asked to draw a plan of action post training.
Findings.

• 27 participants who are involved in public education were recommended by their organizations to participate in this inaugural workshop.

• 20 Female and 7 male.

• Overall the participants found the workshop engaging, informative and educative.

• Participants appreciated their knowledge gaps and felt they had gained confidence and skills to talk about cancer.
Findings: Challenges.

• Cultural inertia and internal resistance to change.
• Lack of shared goals and mismatched expectations between medical fraternity and advocates,
• Variations in the advocates backgrounds, experience and education.
• Lack of buy-in regarding advocate’s credibility as legitimate partners.
• Medical Scepticism:
  ✓ Can advocates understand complex science?
  ✓ What expertise do they offer?
  ✓ Why should they learn science?

Conclusions & Recommendations

• A basic understanding of cancer science is a critical component of cancer advocacy work.

• Cancer control advocates should have a mandatory foundation training on cancer before engaging the public, media and policy makers.

• Oncologists and Policy Makers need to recognize the contribution of advocates to cancer control and treat them as valuable allies.

Mayer (2013)
• Mayer M.A. Seat at the table: a research advocate’s Journey. J. Particip. Med. 2009; 1e14
• Mayer M.A. Patient advocacy in research: merely an after thought?. Patient. 2011; 4: 69-71