

Symposium title: Cancer screening and prevention in people with intellectual disabilities

Submission type: 90 minute symposium

Theme: Equity

Corresponding author: Dr. Maarten Cuypers, E-mail: maarten.cuypers@radboudumc.nl

Moderator: Dr. Margaret Denny, University of Maribor, Maribor, Slovenia

denny.margaret@gmail.com

Symposium summary

Subpopulations with limited health skills and more complex health needs, such as people with intellectual disabilities (ID) are potentially underserved by generic cancer prevention and screening policies. This contributes to disparities across the entire cancer spectrum, leading to poorer oncological outcomes and ultimately premature mortality.

Understanding of how to optimize cancer care to people with ID, starting with cancer prevention and screening, is scarce. People with ID are overlooked in population monitoring and routine data (i.e. not identifiable as having an ID), and thus missing in relevant statistics informing policy and practice. Moreover, people with ID are often excluded from scientific studies due to legal (e.g. difficulties in obtaining informed consent) or methodological issues (e.g. generating unwanted heterogeneity), which limits the development of new scientific knowledge. In this symposium, we will address relevant issues related to cancer and ID, with a specific focus on screening and prevention. First we will introduce the specific relationship between ID and cancer, next, we will give an overview of cancer screening and prevention policies across Europe and their attention for disability groups, and finally we will present a proposal for a collaborative research network to build equitable, disability-inclusive cancer prevention policies.

Abstract

Title: Cancer and intellectual disabilities; current knowledge

Authors:

Amina Banda, MSc. – Radboud university medical center, Nijmegen, The Netherlands

Dr. Maarten Cuypers – Radboud university medical center, Nijmegen, The Netherlands

Presenting author: Dr. Maarten Cuypers, E-mail: maarten.cuypers@radboudumc.nl

Background - Approximately 1.5% of the population in western countries is diagnosed with an intellectual disability (ID). ID is characterized by limitations in cognitive functioning and adaptive behavior with onset during childhood. Besides care needs directly emerging from the disability, are people with ID overrepresented in chronic disease groups, challenged in maintaining healthy lifestyles, and limited in health literacy and other health (decision-making) skills. This has impact for (preventive) cancer care as well, but knowledge among care professionals in this area is limited.

Methods – An overview is given of key findings from literature reviews, and population studies on the entire cancer spectrum in relation to ID.

Impact on practice – Results indicate care providers in both primary care and oncology care need to be aware of the following:

- 1) Some (genetic) ID syndromes include elevated risks for tumor development;
- 2) The age- and sex-group specific cancer incidence in the ID population is different from what is known from the general population;
- 3) People with ID experience barriers in (timely) accessing preventative care, screening, and cancer treatment;
- 4) People with ID die more often from cancer, and at younger ages than people without ID.

Discussion – Disability inclusive cancer care may require adjustments to routine care, although knowledge to design such adjustments is scarce. Improving awareness for the specific needs of the ID population as presented here is a first step towards more equitable cancer care.