Maternal Orphans due to Cancer

The intergenerational impact of cancer deaths in women

International Agency for Research on Cancer





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Summary

Cancer is the second most common cause of death worldwide. At younger ages, cancer deaths disproportionately affect women more than men. However, before 2022, there were no global estimates of the number of maternal orphans due to cancer, i.e. children younger than 18 years whose mothers have died from cancer. This gap in knowledge is critical because orphans often face numerous health and educational challenges, which persist throughout their lives.

Recognizing the lack of data on the number of children affected by the loss of a mother to cancer, IARC embarked on an ambitious effort to estimate the global number of maternal orphans resulting from cancer-related deaths in women in 2020. In this endeavour, the scientists "Each year more than 1 million children lose their mother due to cancer."

– Dr Florence Guida, Environment and Lifestyle Epidemiology Branch, IARC

aimed not only to provide a global figure but also to break it down by country, by region, and by the type of cancer causing the maternal deaths.

The staggering scale of the estimated 7 million maternal orphans due to cancer in 2020, 1 million of whom were newly orphaned in that year, serves as a stark reminder of the urgent need to reduce preventable premature deaths from cancer and address the needs of the affected generation of children.

Introduction

Cancer resulted in almost 10 million deaths worldwide in 2020. This mortality burden has immense emotional and financial impacts at the personal, family, health-system, and societal levels. Less often considered is the impact of cancer

Call to action



Governments in low- and middleincome countries are encouraged to accelerate the implementation of the WHO Global Breast Cancer Initiative and the WHO Cervical Cancer Elimination Initiative.



Researchers are encouraged to assess the needs of the population orphaned due to cancer.



Governments and civil society are encouraged to provide support to families and communities caring for children orphaned due to cancer so that they are not further disadvantaged in life.

Key messages

- Every hour, 120 children lose their mother due to cancer; that is 1 million children per year.
- Almost half (48%) of the new maternal orphans due to cancer in 2020 were in Asia, and more than one third (35%) were in Africa.
- Children in lower-income countries had higher risks of becoming a maternal orphan due to cancer than children in high-income countries, exacerbating inequities.
- Almost half of new maternal orphans were due to deaths from breast cancer and cervical cancer, two cancer types that have the potential of low mortality rates.

in adults on their children. Children can be affected during the period of their parent's cancer care, because of the prolonged physical, psychological, and financial demands of the course of treatment. If the parent eventually dies, their children can also be affected beyond this parental death.

Globally, most cancer deaths (~70%) occur in people who are 60 years or older at the time of death. By these ages, their offspring are already adults. In contrast, when a cancer death occurs in a younger adult, their children may still be minors (i.e. younger than 18 years) when the parent dies. According to the United Nations Children's Fund (UNICEF) definition, a child (younger than 18 years) who has lost one parent is a single orphan, whereas a child who has lost both parents is a double orphan. Thus, a cancer death of a young woman can result in maternal orphans. In countries with young demographics, most of which are lower-income countries with relatively low cancer survival, the average age at cancer diagnosis and at cancer death is younger than in older populations: thus, when an adult dies from cancer, their death is more likely to result in cancer orphans. Despite this, before 2022, there were no global estimates of the number of cancer orphans.

Gaining insights into the impact of cancer through a family-centred approach

IARC was alerted to the overlooked issue of orphans due to cancer in a recent breast cancer cohort study in Africa: the African Breast Cancer - Disparities in Outcomes (ABC-DO) study. In ABC-DO, the need to conduct active telephonic follow-up of the study participants enabled study investigators to ask the woman's next of kin about the impact of the woman's death on the family. In these interviews, reports of concerns about children left motherless were surprisingly frequent; families expressed concerns about the children's care, education, and well-being. Moreover, the financial toxicity of what was ultimately failed cancer treatment exacerbated the situation, because families were already financially stretched when the woman died. At times, the familial situations echoed those of HIV orphans over the past three decades, with children being taken care of by grandparents.

In absolute terms, there were more maternal orphans due to breast cancer deaths than there were breast cancer deaths. Among deaths that occurred before age 50 years, for every 100 women who died from breast cancer, there were more than 200 children who newly became maternal orphans. Thus, building on this cohort study's observations, IARC scientists sought to gauge the extent of maternal orphans globally. They estimated the number of maternal orphans due to cancer deaths in 2020 and described the distribution by country and cancer type.

Why maternal orphans?

The initial focus was on maternal orphans due to cancer, rather than paternal orphans or any orphans, for several reasons. First, among cancer deaths before age 50 years, women are disproportionately affected compared with men, and especially so in lowincome countries, because of low survival from common female-dominant or female-specific cancers: breast cancer and cervical cancer. Second, the higher fertility of women in lower-income countries is also characterized by long reproductive lives, including a late maternal age at last birth, i.e. births of children who may still be younger than 18 years if and when their mother dies. The third reason is methodological, because data from fertility surveys are more readily available for women

Testimonials of family members of deceased patients with breast cancer in the ABC-DO study

"She left a younger child of 2 years with no help, yet most of the land was sold in order to buy the prescribed drugs for her treatment." – Next of kin in Uganda

"She was supporting her family, paying school fees for her children, so now they may not get the education she wanted." – Next of kin in Uganda

> "She was a single parent with young children. Now the grandmother has to raise them." – Next of kin in Namibia

Methodology behind the global estimates of maternal orphans due to cancer

The methodology behind these estimates takes the number of cancer deaths in women in 185 countries or territories worldwide, according to their age at death (15–67 years), and multiplies this number by the estimated number of children each woman had who were still alive and younger than 18 years when she died. Cancer mortality data were based on IARC estimates (GLOBOCAN 2020). The number of children who were still alive was based on the fertility in 2002–2019 of the woman's birth cohort. Fertility data were obtained from the United Nations World Population Prospects 2019. The estimates of the number of children who were still alive accounted for previous child mortality (i.e. families who experienced the loss of a child before the mother died). The estimates also took into account that the number of pregnancies a woman has affects her risk of certain cancer types. Thus, the previous parity of a woman who developed (and died from) cancer would differ from the average parity of her birth cohort. An example of this is the lower average parity of postmenopausal women with breast cancer.

than for men. For a comprehensive assessment of orphans due to cancer, it will be imperative to extend this work to estimates of the number of paternal orphans, too, and to examine the impact on children's lives after the loss of either parent due to cancer.

Global estimates of maternal orphans due to cancer

IARC scientists estimated that as a result of the 4.4 million cancer deaths in women worldwide in 2020, there were 1.04 million newly orphaned children. Almost half (48%) of these new maternal orphans were in Asia, and more than one third (35%) were in Africa (see Figures 1 and 2). In Asia and Africa, six countries accounted for two fifths of the worldwide total of maternal orphans: India, China, Nigeria, Indonesia, Ethiopia, and Pakistan.

In terms of a child's risk of orphanhood due to cancer, there was a worrying overall trend, with a higher risk in countries with a lower Human Development Index (HDI), ranging from 121 orphans per 100 000 children in Malawi to 15 orphans per 100 000 children in Malta (world average, 40 orphans per 100 000 children). Thus, children who are already experiencing



Fig. 1 World map of new maternal orphans due to cancer per 100 000 children in 2020.

disadvantages in life have the highest risk of maternal orphanhood due to cancer.

Most newly orphaned children (68%) were 10 years or older when their mother died; 21% were aged 5–9 years, and 11% were younger than 5 years. The average age of new maternal orphans for most countries (166 of 185 countries, 90%) varied between 10.5 years and 12.5 years, with a clear positive relationship of older age at orphaning in countries with higher HDI. Finally, an estimated 7 million children were prevalent maternal orphans due to cancer in mid-2020, with a similar geographical distribution to that of new maternal orphans.

Cancer types contributing to maternal orphans due to cancer

One quarter (25%) of new maternal orphans due to cancer in 2020 had mothers who died from breast cancer, 20% from cervical cancer, and 18% from gastrointestinal cancers (dominated by cancers of the liver, stomach, oesophagus, and colorectum) (see Figure 3). The rankings of these top three cancer types varied between regions and with HDI, but breast cancer deaths always ranked either first or second. In Eastern and Southern Africa, cervical cancer deaths led to more maternal orphans than breast cancer deaths.



Fig. 2 New maternal orphans due to cancer in 2020 by geography.

Fig. 3 New maternal orphans due to cancer in 2020 by cancer type.

"Accelerating the implementation of the WHO Global Breast Cancer Initiative and the WHO Cervical Cancer Elimination Initiative has the potential to avert not only millions of preventable cancer deaths in women but also the associated, often-overlooked, intergenerational consequences of these deaths."

> - Dr Valerie McCormack, Environment and Lifestyle Epidemiology Branch, IARC

Fortunately, the large percentage (45%) of maternal orphans due to deaths from breast cancer and cervical cancer is being tackled by two cancer initiatives of the World Health Organization (WHO): the Global Breast Cancer Initiative and the Cervical Cancer Elimination Initiative. The success of these two initiatives - through improvements in breast cancer survival, and through human papillomavirus (HPV) vaccination programmes and cervical cancer screening and treatment - will lead not only to averted cancers and related deaths but also to fewer orphans due to cancer.

Potential consequences of orphanhood

Previous studies have unveiled the potential consequences of orphanhood (from any cause of parental death) and thus the need to support such children. Orphanhood can have long-term impacts and affect multiple dimensions of life, health, and development. These impacts have been seen across very diverse settings, including in both lowand high-income countries. Studies have documented consequences on mental, physical, and emotional health, violence, educational attainment. family poverty, and risk of teenage pregnancy. In recognition of these needs, in some countries cancer associations provide the educational means for the orphaned children. There are few specific studies of the lives of orphans due to cancer, and more studies are warranted, because their situation may be complicated by the specific financial toxicity of cancer care in some countries, or by the strong genetic risks of cancer in a small proportion of such orphans.

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Key references

Galukande et al. (2021). JAMA Oncol. 7(2):285-9. PMID:33355599

Guida et al. (2022). Nat Med. 28(12):2563-72. PMID:36404355

Ferlay et al. (2020). Global Cancer Observatory: Cancer Today. Lyon, France: International Agency for Research on Cancer. Available from: https://gco.iarc.who.int/today.

Kidman et al. (2021). Nature. 596(7871):185-8. PMID:34373628

UNAIDS, UNICEF, and USAID (2004). Children on the brink 2004: a joint report of new orphan estimates and a framework for action. Available from: https://data.unaids.org/publications/external-documents/unicef_childrenonthebrink2004_en.pdf. Ginsburg et al. (2023). Lancet. 402(10417):2113-66. PMID:37774725

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