# Disparities and inequalities in cancer care and outcomes

in patients with severe mental illness: Call to Action

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#### **ABSTRACT**

**Objectives:** People with severe mental illness (SMI) are at extreme risk of being stigmatized and to receive poor quality physical care. It has been demonstrated that they have higher morbidity and poorer prognosis of several medical diseases than the general population, with an at least 10-20-year reduction in life expectancy.

**Methods:** A special issue of *Psycho-Oncology* focusing on cancer care among patients affected by SMI was called by the Editorial Board of the journal, with the aim to explore cancer health disparities and inequalities among people with SMI, mortality from cancer, problems of communication between multidisciplinary oncology and psychiatric teams and need for more structured intervention (i.e. screening, prevention, treatment).

**Results:** Authors from eight countries contributed. The problem of stigma and barriers to cancer care provision for patients with SMI were studied (e.g. the complex nature of SMI and healthcare providers' misunderstanding of SMI). Key barriers were related to both patients, clinicians and institutional problems, such as fragmentation of care. A higher mortality for cancer and poor knowledge about cancer risk-factors was shown in patients with SMI. Models of intervention were also proposed.

**Conclusions:** Several conclusions have been recommended by the authors, such as the need for guidelines and clinical procedures specific for cancer care in mental health settings; large-scale studies to address the disparities of care in people with SMI; a larger vision of psychosocial oncology as the facilitator of the liaison between oncology and psychiatry.

**Keywords:** Cancer, inequalities, severe mental illness, schizophrenia, bipolar disorders, psycho-oncology, mental health, provision of care, screening, mortality

treatment of physical disorders.<sup>7</sup>

# INEQUALITIES OF CARE AND SEVERE MENTAL ILLNESS

When speaking about inequalities and disparities in cancer care and psychosocial oncology across countries and different segments of the population,<sup>1</sup> it is crucial to consider the problem of people with severe mental illness (SMI), defined here as a cluster of disorders, namely schizophrenia spectrum disorders (i.e., schizophrenia, schizoaffective disorders), bipolar disorders, severe depression, and other psychotic disorders. Those affected are at extreme risk of being marginalized and stigmatized by society with negative consequences in terms of disability, poor quality of life, unemployment, low access to institutions providing care and a worsening impact on physical health.<sup>2</sup>

This area has come to the attention of psychiatry for many years, given the dramatic findings indicating that, in general, patients with SMI have a higher morbidity rate of somatic diseases which, in a vicious circle, increases in turn the sense of marginalization and disability and decreases the level of quality of life.<sup>3</sup> Also, higher morbidity has been related to a poorer prognosis of the medical disease and a 2-3 times higher average mortality compared to the general population, which translates to at least a 10-20-year reduction in life expectancy.<sup>4</sup>,<sup>5</sup> Ten years ago, Thornicroft <sup>6</sup> underlined that poorer physical healthcare and premature mortality in people with SMI is a "scandal" which contravenes the international conventions for the right to health for all segments of the population, especially the most vulnerable. Data show in fact that patients with SMI receive poor quality health care, including prevention, screening, and

Although most of the studies have mainly concentrated attention on diseases other than cancer (e.g., cardiovascular diseases, diabetes, respiratory tract diseases, infectious disease, including HIV infection and COVID related illnesses), it is not surprising that all the above-mentioned aspects can be confirmed when analysing the data coming from oncology. 8,9,10

There are in fact several factors that have been summarized as contributors of poor health care and higher mortality in people with SMI and cancer. Among these, smoking habits, harmful use of alcohol and other drugs, sedentary behaviour and lack of physical exercise could be factors. Others, such a possible iatrogenic effects of medications (e.g., antipsychotics), contribute. Furthermore, inequitable access to health care services, in part because of socioeconomic problems and poverty and lack of education, in part because of alienation from the

social network, reduced help-seeking behaviour, and a general lack of awareness of physical problems, has been underlined.

Regarding the problem of morbidity of cancer, metanalyses has shown a lower rate of cancer screening (e.g., breast, cervical, prostate) in patients with psychiatric disorders. This has been demonstrated particularly in people with schizophrenia and, to a less extent, in those with severe mood disorders. <sup>11,12</sup>

Once a diagnosis of cancer is made, treatment seems to be characterized by disparities with respect to the general population. People with SMI are less likely to be allocated to correct treatment protocols for cancer<sup>13</sup> and more likely to maintain at-risk behaviours and to have poorer adherence to treatment. Therefore, and not surprisingly, patients with SMI and cancer live fewer years than patients without SMI and die in an advanced phase of the disease. It has also been reported that patients with SMI do not see specialists other than psychiatrists, do not correctly receive analgesics, and do not have optimal levels of palliative care. <sup>141516</sup>

A further issue relates to problems that oncology teams have in caring for people with SMI and cancer, since the patient's unusual behaviour, inappropriate affect, presence of psychosis (e.g., delusions and hallucinations), or cognitive symptoms (e.g., impaired attention, reducing the patient capacity to understand the meaning of medical and surgical procedures), dysfunctional coping (e.g. pathological denial) and behavioural problems (e.g. poor adherence), often contribute to difficulties in communication and management <sup>17</sup>

#### OVERVIEW OF THE SPECIAL ISSUE CONTENT

With this background, this special issue of *Psycho-Oncology* was considered extremely necessary, if not mandatory, by the Editorial Board of the journal. Under the auspices of the World Psychiatric Association Section on Psycho-oncology and Palliative Care, it specifically focuses on cancer health disparities and inequalities among people with SMI, mortality from cancer, problems of communication between multidisciplinary oncology and psychiatric teams, and need for the development of specific guidelines for better cancer care in mental health settings and for a larger vision of psychosocial oncology, advancing the strong need and liaison between oncology and psychiatry settings.

To our knowledge, this is the first issue of a scientific journal completely dedicated to this important and urgent area. Several authors from eight different countries and with expertise in research and clinical cancer care for patients with SMI contributed to the volume. Among the

papers submitted to the call, 14 of the submissions from 8 countries are included in this special issue, including literature reviews, research papers, and clinical correspondence reports.

# Stigma, Marginalization and Communication Problems

Stigma, in terms of both self- and social stigma, is one of the main topics on which the psychiatric literature has concentrated attention over the last 40 years. 192021 In this issue, D'Alton et al.<sup>22</sup> explore the opinions of health care cancer professionals, including oncology and psychiatry consultants, nurses, psychologists and social workers. The study found that there were barriers to cancer care provision for patients affected by SMI: fragmentation of care; healthcare providers' understanding of SMI; complex nature of presentation; and specialized care needs. In the Japanese study, by analyzing the responses of 439 professionals, Etoh et al. 23 categorized issues related to communication barriers into a series of dimensions: patient factors; isolation and lack of support; attitudes of psychiatric professionals attitudes of cancer care professionals. A review by Lehay et al.<sup>24</sup> investigated the barriers to, as well as facilitators, in accessing cancer care for people with SMI. They found that key barriers were related to patients' uncontrolled psychiatric symptoms and the adverse impact of their symptoms on engaging with cancer care. Also, clinician barrier-attitudes were found to play a role, especially stigmatising attitudes from clinicians and other staff towards individuals with SMI. On the other hand, being connected with mental health services and controlled psychiatric symptoms is considered a key patient facilitator to accessing cancer care and completing cancer treatment. A very specific and important point was raised by McFarland et al.<sup>25</sup> in the USA. In a series of psychiatric consultations for patients with SMI and cancer, they found that shared decision making was often a problem. As the authors demonstrated, however, patients with SMI had a high prevalence of intact decisional capacity. This raises several concerns regarding the hypothesis and clinical assumption that patients with SMI and cancer may lack decisional capacity based on successive vulnerability.

# **Poor Access to Care**

The study by Murphy et al.<sup>26</sup> involving a large sample of Medicaid enrollees in Maryland USA, found suboptimal cancer screening rates among Medicaid enrolled adults with SMI, especially in patients with a co-occurring substance use disorder and living in smaller counties with lower mean incomes. Interestingly, black Medicaid enrollees with SMI were more likely than white

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enrollees to receive cervical, breast, and colorectal cancer screening. In an Italian study,<sup>27</sup> comparing patients with SMI and a matched sample of patients without SMI attending primary care outpatient clinics, the former showed a lower participation to occult stool blood screening test, Pap smear test and mammography; had a higher prevalence of current and past smoking habits and a lower awareness towards their own physical symptoms and their perception of risks for cancer. As a very important point, they had poorer knowledge about cancer risk factors, indicating the need for educational programs. Finally a review by Park et al.<sup>28</sup> of studies examining health inequalities and the compounding factors faced by patients with SMI patients in low- and middle-income countries, showed disparities in vaccination, screening and prevention and the urgent need to change social stance towards SMI, including integration of psycho-oncology in the care of patients with SMI and cancer.

# The Problem of Suicidal Thoughts and Suicide

Suicidal thoughts and suicide determined by cancer is an important clinical area in psychosocial oncology, <sup>29</sup> since a 2-2.5 higher rate of suicide has been found among the oncology population in comparison with the general population.<sup>30,31</sup> Several factors have been indicated as a risk for the increase of suicide such as; depression, male gender, loneliness and social isolation, advanced stage of cancer, first year after diagnosis and type of cancer (e.g., pancreas, head and neck cancer). 32 In this issue, an Egyptian study of 59,580 patients with gastric cancer confirmed a higher suicide mortality risk in divorced patients, patients not recommended for surgery because of an advanced stage of illness, and those who were males.<sup>33</sup> A German study of more than 2,000 cancer patients who were administered the Composite International Diagnostic Interview to make an ICD-10 psychiatric diagnosis according showed that about 7% of the population was characterized by thoughts of death without suicidal ideation and a further 4% by thoughts of death, suicidal ideation, and suicide plans.<sup>34</sup> Death wishes occurred in both groups and were associated with a significantly higher risk for any ICD-10 mental disorder among those examined (i.e. depression). However, no study examined this topic in patients Data regarding the relationship between cancer and suicide, which is one of the most important causes of death in this population, should urgently be explored.

# **Cancer Mortality**

Mortality in patients with SMI, especially those affected by schizophrenia and schizophrenic spectrum disorders, has been the object of several studies which indicated a higher mortality

rate in patients with SMI and cancer in several countries.<sup>35</sup> In this issue, these data were confirmed by the only research submitted on this topic, a 10-year follow-up study of almost 3,000 patients with schizophrenia and bipolar spectrum disorders who died from cancer in Northern Italy.<sup>36</sup> The authors found a higher mortality rate (50% higher) for cancer in patients with SMI with respect to the general population and a higher proportion of deaths in the younger age class among patients with SMI than among the general population.

#### **Intervention**

Despite what has been said, a few interventions have been proposed to firmly and concretely address the problem of cancer in patients with SMI. The work done by Irwin et al.<sup>37,38</sup> with respect to this, is extremely important. The authors defined a model to manage the multilevel barriers to cancer care for people with SMI, including pervasive mental health stigma, patient factors (lack of trust), clinician factors (inadequate training), and healthcare system factors (fragmented mental health and cancer care). Callaway et al.<sup>39</sup> summarize the work done in Boston, Massachusetts, describing how it is possible to engage diverse stakeholders by establishing a coalition, to establish trust and to collaborate across sectors, including mental health. Also sharing conceptual foundations and the same language among stakeholders by facilitating conversations about discrimination and SMI, is a way for oncology and mental health clinicians to collaborate and to raise awareness about the inequity of cancer care for people with SMI.

# PRIORITIES FOR FUTURE RESEARCH

A series of steps are necessary without further delay in political and research agendas for patients with SMI and a series of aspects should be the focus of future research.<sup>40</sup> Research should be concentrated on

- (1) how to develop guidelines and clinical procedures for early detection and early treatment.
- (2) High-quality, large-scale studies to help address the disparity between people with SMI and the general population in both cancer screening uptake<sup>41</sup> and treatment.<sup>42</sup>
- (3) The effectiveness of timely treatment and rehabilitation, reducing the delays between the diagnosis of cancer, and the initiation of treatment should be demonstrated.
- (4) Research dealing with methods to promote healthy behaviour in this vulnerable segment of the population is necessary, with studies showing the effects of anti-smoking, anti-alcohol and anti-drug campaigns.

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(5) Research needs to examine how to increase the dialogue and liaison between cancer and mental health services to deal with the multiple problems of patients with SMI, to improve the attitudes towards people with SMI, to increase social acceptance and to reduce stigma and provide all patients with the most proper and appropriate cancer treatment.

### **CONCLUSIONS**

As noted almost twenty years ago by Phelan,<sup>43</sup> although in most countries reform in mental health care has led to the closure of long stay mental hospitals and the development of community mental health services, physical health care is still not given priority. Recently, the World Health Organization (WHO) has developed specific guidelines with evidence-based recommendations for the management of physical health conditions and reduction of their associated risk factors in people with SMI.<sup>44</sup> However, cancer and SMI is still not part of the WHO agenda. Since cancer is one of the most common diseases world-wide and *per se* associated with significant psychosocial problems and psychopathological consequences, it is time to change.

Much remains to be done and future work needs to focus more on the role that psychosocial oncology has in the area of psychiatric disorders and illnesses. This special issue of *Psycho-Oncology* is a further step forward in bridging the gaps for people suffering from serious psychiatric conditions.

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