CHAPTER 3.

Why social inequalities matter in the cancer continuum

Diana Sarfati

What do we mean by social inequality in the cancer continuum?

Social inequality in the cancer continuum refers to systematic differences between social groups that affect people's risk of developing cancer, the likelihood that they receive effective and timely (or any) treatment for the cancer, whether they survive, and whether they have access to palliative care. Such inequality can occur on many axes, including, but not limited to, a person's socioeconomic status (SES), race or ethnicity, sex, disability, sexuality, and geographical location. Marked, persistent social inequalities occur across the cancer continuum both between and within countries. They reflect the importance of social, economic, environmental, historical, and political

contexts in determining who develops cancer, what kind of cancer they develop, and whether they survive or die from it. The relationships between these determinants and cancer outcomes are neither linear nor simple. They operate through multiple intersecting pathways, reflected in differential exposure to risk factors such as social factors (e.g. resources and support), living conditions (e.g. housing and overcrowding), behavioural factors (tobacco use, unhealthy diet), and different access to and through health services.

Terminology in this field is somewhat contentious. For clarity, the focus of this book is on differences that occur between social groups and that are amenable to reasonable action (Kawachi et al., 2002). The term inequity implies a judgement that dif-

ferences are inherently unjust, for example the uneven distribution of access to cancer care services. This element of unfairness can sometimes be contentious and difficult to determine. The term inequalities, referring to differences between population groups, will therefore be used in this book (Kawachi et al., 2002). The term disparities is very closely aligned with inequalities, and is more commonly used in United States literature on this topic (see Box 3.1).

Why should we care about social inequalities in cancer?

Social inequalities occur at every step of the cancer continuum

Social inequalities are evident at every step of the cancer continuum, starting from the individual's exposure

Inequity in health:

"Health inequity refers to those inequalities in health that are deemed to be unfair or stemming from some form of injustice.... Because identifying health inequities involves normative judgment, science alone cannot determine which inequalities are also inequitable, nor what proportion of an observed inequality is unjust or unfair" (Kawachi et al., 2002).

Inequalities in health:

"Health inequality is the generic term used to designate differences, variations, and disparities in the health achievements of individuals and groups" (Kawachi et al., 2002).

Disparities:

Disparities in cancer are defined by the United States National Cancer Institute as "adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups" (National Cancer Institute, 2018).

to risk factors and the likelihood of developing cancer, to whether information relating to the cancer is collected and counted, through access to screening and diagnostic facilities, and even to fundamental palliative care.

Social patterns of cancer incidence and mortality have been documented for decades, with many cancers occurring more frequently among groups with lower SES and other underserved populations. This is particularly true for cancers related to tobacco use (such as lung and oral cancers), chronic infections (including cervical, stomach, and liver cancers), and exposure to some dietary, reproductive, occupational, and environmental factors (see Chapter 7). There are also clear differences in the pattern of cancer incidence and mortality across countries according to their Human Development Index, which provides a measure of social and economic progress (Bray et al., 2012). Countries of lower Human Development Index have a substantially higher proportion of cancers associated with chronic infection, but cancers associated with reproductive and dietary risk factors, which predominate in high-income countries (HICs), are also quickly increasing in importance.

The most fundamental requirement for identifying, monitoring, and addressing inequalities in cancer is the ability to generate relevant information from a functional cancer registry and mortality vital registration. Despite some progress, many low- and medium-income countries (LMICs) still do not have the capacity to produce even basic cancer intelligence. Of the 71 countries reporting such data in the CONCORD-3 study. only 27 were LMICs (Allemani et al., 2018). Within HICs, poor cancer outcomes among some underserved groups remain largely invisible because of a lack of adequate data, notably the plight of Indigenous populations (Sarfati et al., 2018).

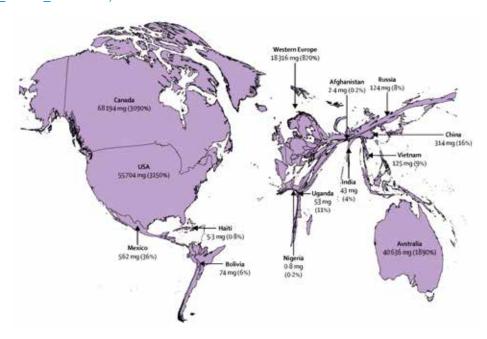
People diagnosed with cancer in LMICs and among the most vulner-

able groups in HICs are more likely to be diagnosed with advanced disease, and have poorer survival (Dalton et al., 2008; Ellis et al., 2012; Cunningham et al., 2015; Singh and Jemal, 2017; Allemani et al., 2018). In LMICs there is also a lack of access to timely and effective cancer diagnosis and care, resulting in exceptionally poor outcomes for those diagnosed (Atun et al., 2015; Sullivan et al., 2015; Allemani et al., 2018; Wilson et al., 2018). Cancer screening programmes in LMICs are often either not available or poorly developed (Sankaranarayanan, 2014). In HICs, there is consistent and troubling evidence of ethnic or racial disparities in cancer care and outcomes, as well as evidence of less access to cancer screening, poorer cancer care, and less favourable outcomes among other disadvantaged groups (Smedley et al., 2002; Woods et al., 2006; Hill et al., 2013; Cunningham et al., 2015).

In many LMICs, the outcomes for cancer remain dismal. In countries without universal health coverage or other adequate safeguards, a diagnosis of cancer can be financially catastrophic for individuals and their families because of unaffordable out-of-pocket payments (Carrera et al., 2018; Jan et al., 2018).

Access to palliative care is a neglected aspect of global health (Fig. 3.1), and many people with cancer, including children in LMICs and underserved people in some HICs, die without access to adequate symptomatic relief, despite its relative affordability (Knaul et al., 2018). The lack of effective palliative care for many of the world's most vulnerable people has recently been described as a "medical, public health, and moral failing and a travesty of justice" (Knaul et al., 2018).

Fig. 3.1. Distributed opioid morphine-equivalent and estimated percentage of need that is met for serious health-related suffering. Source: reprinted from Knaul et al. (2018), copyright 2018, with permission from Elsevier. Data from International Narcotics Control Board and WHO Global Health Estimates, 2015 (http://www.who.int/healthinfo/global burden disease/en).



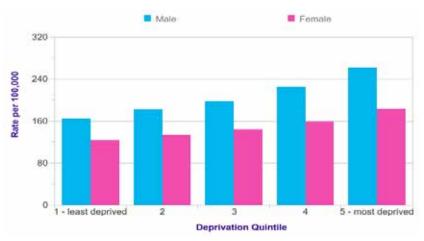
Despite these stark inequalities across the cancer continuum, cancer research remains focused on basic science and expensive treatments; there is very limited research on defining, identifying, and addressing social disparities in can-

cer (Krieger, 2005). Furthermore, most cancer research occurs in the context of HICs. For example, 73% of cervical cancer research is carried out in HICs compared with only 0.7% in low-income countries, despite the disproportionate burden of

cervical cancer in LMICs (Ginsburg et al., 2017).

Each of these elements – social inequalities in cancer prevention, surveillance, treatment, and survival, as well as access to palliative care – is explored across several chapters of this book.

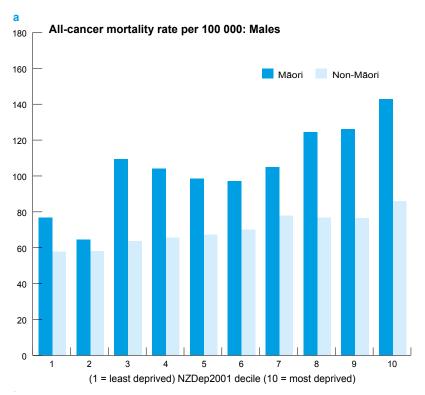
Fig. 3.2. Mortality rates (per 100 000) by deprivation quintile in England for all cancers combined (excluding non-melanoma skin cancers); 2007–2011 (European age-standardized).

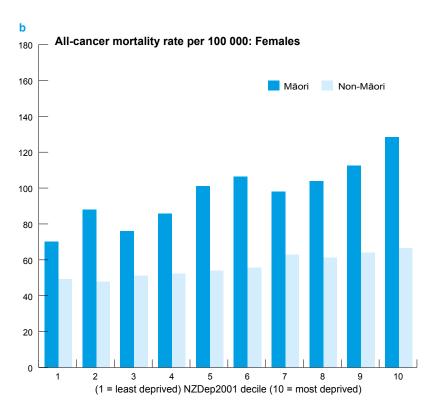


Social inequalities affect everyone

Although the poorest of the poor and the least privileged groups tend to have the worst health at both individual and country level, there is a demonstrable gradient highlighting how cancer mortality increases through all strata from those living in areas of least to greatest deprivation. For example, data from England show that cancer mortality is higher among those living in more deprived areas, with a clear gradient evident for both men and women (Fig. 3.2).

Fig. 3.3. Cancer mortality (per 100 000) in New Zealand by deprivation decile and ethnicity for (a) males and (b) females, age-standardized. NZDep, New Zealand Deprivation Index. Source: reproduced from Robson et al. (2010), under a Creative Commons Attribution 4.0 International Licence.





A similar pattern exists within New Zealand. A higher level of (area-based) deprivation is associated with higher mortality from cancer among males (Fig. 3.3a) and females (Fig. 3.3b). There are two additional points to note: (i) although a gradient is evident for both Māori and non-Māori populations, it is steeper for Māori, and (ii) at every level of deprivation, cancer mortality among Māori populations is substantially higher than that among non-Māori populations. These observations suggest that the disparities between ethnic groups cannot be explained by differences in SES only (Krieger, 2005; CSDH, 2008; de Souza et al., 2016).

The presence of such gradients means that interventions aiming to address inequalities have a potentially positive impact (theoretically, at least) on the health of entire populations. However, within and between countries some groups are disproportionately negatively affected by cancer, such as those living in poverty, Indigenous populations, ethnic minority groups, and those with mental illnesses (Valery et al., 2006; Dalton et al., 2008; Blakely et al., 2011; Bray et al., 2012; Ellis et al., 2012; Kisely et al., 2013; Cunningham et al., 2015; DeSantis et al., 2016; Singh and Jemal, 2017; Australian Institute of Health and Welfare, 2018; Bryere et al., 2018; Tweed et al., 2018). These groups have the potential to gain the most from such interventions.

The associations are strong and persistent

There are stark inequalities in cancer incidence and survival between those living in LMICs and those living in HICs. Although overall cancer incidence is higher in HICs, cancer rates are increasing more rapidly in

LMICs; the pattern of cancer sites is also different between HICs and LMICs (Farmer et al., 2010; Bray et al., 2012; de Souza et al., 2016). Indigenous populations, people living in poverty, and those who are part of ethnic minority groups or other disadvantaged groups tend to experience different patterns of cancer incidence; poorer cancer survival rates are observed among such groups compared with more privileged people, within both higher- and lower-income countries (Dalton et al., 2008; Blakely et al., 2011; Singh and Jemal, 2017; Allemani et al., 2018; Australian Institute of Health and Welfare, 2018; Bryere et al., 2018). Strong and persistent patterns exist, with systematic differences between social groups seen in nearly every context where they are investigated. The magnitude of the association with social factors is often greater than the association with so-called traditional risk factors for cancer. In New Zealand for example, the risk of cancer in the Māori population is higher than that in European New Zealanders by factors of 3-3.5 for lung cancer, 4-6 for stomach and liver cancers, and 2 for endometrial cancer (Teng et al., 2016; see Chapters 5 and 6 for more details).

Social inequalities are amenable to change

Social inequalities in cancer outcomes are not inevitable, but changing them is likely to require concerted action at many levels both within and outside of the health sector, and at both local regional and global levels. Strategies and policies focused on root causes, such as addressing unequal power and access to resources between groups, are likely to have an impact on the health status of populations generally and cancer outcomes specifically. For example, global-level strategies that support sexual equality are likely to have a positive impact on women's cancers, particularly in LMICs (Ginsburg et al., 2017). International trade policies that encourage the production of and trade in foods high in saturated fats and sugars, or tobacco, are likely to increase the global burden of obesity- and tobacco-related cancers (Taylor et al., 2000; WHO, 2016). Similarly, policies within and between countries that counteract childhood poverty may have an impact on adult cancers through complex, but generally poorly understood, mechanisms. One example is policies to reduce overcrowding in children's living conditions; less overcrowding is associated with a lower risk of cancer-related chronic infections including Helicobacter pylori and hepatitis B virus (HBV) (Chapter 7; Teng et al., 2017).

Risk factors tend to be more prevalent in the lives of members of the most disadvantaged groups. The reasons for this are complex and multifaceted, including environmental factors (such as the availability of alcohol, tobacco, and healthy food), psychosocial factors (such as stress relating to material hardship, lack of control over one's life, and lack of social support), and cultural, historical, and economic factors (McKee and Shkolnikov, 2001; CSDH, 2008; Mackenbach et al., 2008). Many cancers in LMICs and excess cancers among disadvantaged groups within all countries are amenable to prevention through policies and strategies addressing risk factors of cancer such as: comprehensive tobacco control policies; strategies to address obesity, including supporting a healthy diet and increased physical activity; and policies for equitable access to high-quality vaccination and screening programmes (Farmer et al., 2010; de Souza et al., 2016; Plummer et al., 2016; Ginsburg et al., 2017; Sassi et al., 2018).

Access to affordable, appropriate, and effective health care with a focus on cancer prevention, diagnosis, and treatment is critical. There are vast disparities between the health care available in HICs and in LMICs, with populations in many LMICs experiencing very poor access to cancer treatment services (Farmer et al., 2010; Atun et al., 2015; Sullivan et al., 2015; de Souza et al., 2016; Ginsburg et al., 2017). A lack of universal health coverage in many LMICs is a barrier both to development and to addressing inequalities in cancer outcomes. Progress towards meeting the health-related United Nations Sustainable Development Goals of universal health coverage will have an effect on cancer inequalities both between and within countries (see Chapter 10).

There is also a growing body of evidence supporting the importance of early-life environment as an important determinant of future health (or ill health). Although evidence relating to the effect of early-life exposure to traditional risk factors for cancer (obesity, poor diet, and physical inactivity) on adult cancer risk is inconsistent, the increased risk of cancer in adults exposed to tobacco and to certain infections early in life is conclusive (Teng et al., 2016, 2017).

Evidence of the effectiveness of interventions to reduce inequalities within HICs is largely based on single aspects of complex systems (Masi et al., 2007; Glick et al., 2012; Gorin et al. 2012; McPheeters et al., 2012; National Cancer Institute, 2018). However, comprehensive systems-level approaches are most

likely to succeed (Smedley et al., 2002; Ministry of Health, 2003; Steinberg, 2008; Goss et al., 2009; Department of Health, 2011; National Cancer Institute, 2018), and there is some evidence that such broad, organized approaches may be effective in reducing inequalities within HICs. For example, socioeconomic inequalities in participation in screening for breast cancer and cervical cancer are less likely to be found in countries with organized screening programmes (Palència et al., 2010), socioeconomic disparities are more marked in the USA than in Canada, where universal health care is available (Gorey et al., 2009), and in New Zealand, ethnic disparities in cancer care and survival have decreased over time as a result of organized screening programmes that include an explicit focus on reducing inequalities (McLeod et al., 2010).

Addressing social inequality in health is a global priority

As outlined in Chapter 2, this book focuses on the evidence of the positive impact of aligning global cancer control activity with efforts to improve equality within global health agendas more generally, as well as the action being taken to achieve this goal. It builds on recent work, including the seminal report from the Commission on Social Determinants of Health (CSDH, 2008). A global conference held in Rio de Janeiro in 2011 resulted in the Rio Declaration on Social Determinants of Health (WHO, 2011), with a subsequent World Health Assembly resolution in 2012 endorsing this declaration and the importance of correcting inequities in health (WHA, 2012). These and other activities aim to progress and focus an agenda on supporting health equality within global, regional, and national health and development programmes, and to assist the achievement of the United Nations Sustainable Development Goals (Farmer et al., 2010; UICC, 2013; Stewart and Wild, 2014; UN, 2018). In 2017, the Seventieth World Health Assembly emphasized the importance of cancer prevention and control, with an explicit call to monitor and address inequality (WHA, 2017).

Social inequalities in cancer are often unfair

In the Rio Political Declaration on Social Determinants of Health (WHO, 2011), world leaders reaffirmed that "health inequities within and between countries are politically. socially and economically unacceptable, as well as unfair and largely avoidable". Systematic variations in who develops cancer, the type of cancer developed, and how and whether people survive cancer are seen both within and between countries (Krieger, 2005; Farmer et al., 2010; Blakely et al., 2011; Bray et al., 2012; de Souza et al., 2016; see also Chapters 5 and 6). Where these differences are preventable or amenable to reasonable action, they are not acceptable and require coordinated action. These inequalities reflect the environments in which people are born, live, and work, and, ultimately, the uneven distribution of resources and services within and between countries (CSDH, 2008). The obvious consequence of this is that addressing inequality in health requires action at all levels of society, not just within the health (or cancer) sector.

A clear example of this is the global distribution of infection-related cancers (Chapter 7). About 15% of the world's cancers are caused by infectious agents, particularly *H. pylori*, human papillomavirus (HPV).

HBV, and hepatitis C virus (HCV) (Plummer et al., 2016). The distribution of these cancers is strongly related to the socioeconomic development of countries; less than 5% of cancers in Australia, some European countries, New Zealand, and the USA are caused by infection, but this proportion rises to more than 50% of cancers in some countries in sub-Saharan Africa (Plummer et al., 2016). Within HICs, people who develop and die from infection-related cancers are disproportionately from low-income, ethnic minority, Indigenous, or other underserved groups (Dalton et al., 2008; Blakely et al., 2011; Singh and Jemal, 2017; Australian Institute of Health and Welfare, 2018; Bryere et al., 2018). These cancers are highly preventable with the availability of extremely cost-effective interventions (Farmer et al., 2010; Knaul et al., 2012; Gelband et al., 2015; de Souza et al., 2016; Plummer et al., 2016). The fact that inequalities in these cancers exist is a stark illustration of the inadequacy of current social, political, and economic policies, which, instead of promoting health for all, put the world's most vulnerable people at increased risk.

Global demographic trends are likely to affect inequality

Social inequalities are not static. Changes in population structures may exacerbate social inequalities in cancer outcomes, or create new inequalities. For example, population ageing results in an increasing burden of cancer, with the relative impact being greater for LMICs (Pilleron et al., 2018); without action, such trends are likely to exacerbate the differences between LMICs and HICs. Continuing global urbanization and the growth of urban slums

are leading to substantial challenges for health equity in general (CSDH, 2008). These trends tend to be associated with higher levels of overcrowding, reductions in physical activity, increased consumption of energy-dense and processed food leading to higher rates of obesity, and higher rates of hazardous alcohol consumption. All of these are risk factors for many cancers, and these trends tend to disproportionately affect the most disadvantaged groups (CSDH, 2008). Conflicts and other catastrophic events have also led to the forced emigration of entire populations, resulting in the dissolution of structures and processes to protect the health of those people (see Focus 6).

Social inequalities have major economic implications

There are good economic arguments for investing in health generally (WHO, 2001). If we assume that interventions that reduce inequalities in health have an upwards levelling effect, that is, the health of those in more disadvantaged groups is improved towards the level of those in less disadvantaged groups, then reductions in inequalities also result in better population health overall. In 2015, there were 17.5 million new cases of cancer and 8.7 million deaths from cancer worldwide;

numbers are expected to increase over the next decade, particularly in LMICs (Bray et al., 2012; Fitzmaurice et al., 2017). The global economic impact of cancer is substantial, conservatively estimated at US\$ 1.16 trillion in 2010 (Stewart and Wild, 2014).

There are few studies based in HICs that have explicitly estimated the costs of inequality in either health generally or cancer specifically. However, Mackenbach et al. (2011) found that inequality-related losses accounted for approximately 20% of costs to the health-care system and 15% of costs to social security systems within the European Union. Mackenbach et al. (2011) also found that introducing an equity-focused tobacco policy that reduced smoking by one third among groups with low SES and one guarter among groups with high SES would result in improved health overall and a 7% reduction in costs relating to inequalities.

Although there is a scarcity of relevant research in LMICs, the evidence that exists suggests that there are several interventions that are likely to be cost-effective, even in the most constrained of settings (Horton and Gauvreau, 2015). These interventions relate to preventive strategies such as tobacco control, and the expansion of vaccination programmes and cervical screening

strategies (Horton and Gauvreau, 2015). One estimate is that investing US\$ 100 million in core cancer prevention strategies in LMICs could result in savings of US\$ 100 billion in treatment costs (Knaul et al., 2012). The expansion of cancer treatments, particularly surgery and radiotherapy, would also be expected to reduce the massive disparity in outcomes between those living in HICs and those living in LMICs (Atun et al., 2015; Horton and Gauvreau, 2015; Sullivan et al., 2015).

Conclusions

Inequalities in cancer care and outcomes both between and within countries are persistent and large, resulting in substantial human suffering and economic cost. They affect all populations, with the poorest of the poor most profoundly affected. They are, to a large extent, avoidable. Concerted and coordinated multisectoral action at regional, national, and global levels is urgently needed to prioritize cancer control, strengthen health systems, and monitor progress. The remainder of this book expands on these issues, providing detailed evidence of the extent of inequalities within and between countries, the drivers of those inequalities, and key approaches for tackling them.

Key points

- Marked, persistent social inequalities occur along the cancer continuum both between and within countries.
- Those living in low-income countries and underserved populations within high-income countries are particularly likely to have increased risks of cancers associated with tobacco use, chronic infections, and exposure to some dietary, reproductive, occupational, and environmental factors.
- Those living in low-income countries and underserved populations are less likely to have access to effective diagnostic, screening, treatment, and palliative care facilities.
- Reducing cancer inequalities is likely to require concerted action at many levels both within and outside
 of the health sector.

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