

## Disabilities and Cancer 1



# Cancer detection, diagnosis, and treatment for adults with disabilities

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About 15% of the global population—more than 1 billion people—have a disability. People with early-onset disability are now living into middle and older ages and are therefore at risk for adult cancer. Overall, disabled people are more disadvantaged in social determinants of health and are more likely to have risk factors associated with cancer than people without disabilities. People with disabilities often experience disparities in breast and cervical cancer screening compared with people who do not have disabilities, and patterns in colorectal cancer screening disparities are inconsistent. The minimal evidence that exists relating to the timeliness of cancer diagnosis, treatment, and outcomes for people with disabilities suggests differential treatment and higher cancer-related mortality than for people without disabilities. Worldwide, disabled people face barriers to obtaining cancer care, including inaccessible medical diagnostic equipment, ineffective communication accommodations, and potentially biased attitudes among clinicians. Ensuring equitable cancer care for people with disabilities will therefore require eliminating not only physical but also attitude-based barriers to their care.

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This is the first in a **Series** of two papers about disabilities and cancer

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## Introduction

According to the World Report on Disability,<sup>1</sup> more than 1 billion people worldwide—15% of the global population—have some type of disability. Disability prevalence varies widely across nations and is largely related to population age distribution as disability incidence increases with age. In high-income countries, people with congenital or early onset disabilities are increasingly living into middle and older ages. The risk of developing various comorbid health conditions, including cancer, increases with age for both people with and without disabilities.

Globally “health services are often lower quality, not affordable, and inaccessible for people with disabilities”.<sup>2</sup> Therefore, many people with disabilities who develop cancer face impediments to detecting, diagnosing, and treating their malignancy, which can lead to worse outcomes. This Review examines the challenges people with disabilities have for cancer screening, diagnosis, and treatment, and makes recommendations for improving cancer-related services for people with disabilities.

## Background

“Disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning.”<sup>1</sup> Definitions of disability have evolved over time as the understanding of its causes and consequences has changed.<sup>3</sup> In 2001, WHO defined disability as an “umbrella term for impairments, activity limitations or participation restrictions,” and conceiving “a person’s functioning and disability [...] as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc) and contextual factors”.<sup>4</sup> These contextual

factors include social and physical environments, attitude, and personal characteristics.<sup>4</sup> This biopsychosocial model of disability recognises that disability is not an attribute of individual people, as conceived by the earlier medical model of disability, but instead can result from environmental barriers (eg, inaccessible buildings) that impede disabled people in their daily lives. Thus, disability becomes a human rights and social justice issue.<sup>1,4</sup>

Disabilities are diverse;<sup>1–4</sup> functional limitations can involve mobility, vision, hearing, communication, learning, memory, intellect, mental health, and other aspects of how people interact with their environments and each other. People with disabilities are also diverse in their gender and gender identity, race, ethnicity, sexual orientation, and cultural backgrounds. On average, people with disabilities are disadvantaged in factors considered social determinants of health, with high rates of poverty and unemployment, low educational status, substandard housing, greater exposure to toxic environments, and reduced or no access to transportation.<sup>1,2,5</sup> Globally, disabled people are more likely than those without disabilities to report not having access to health-care services and having unmet health-care needs.<sup>1,2,5</sup>

People with disabilities also have high rates of risk factors for some types of cancers. Although rates differ across disability types, people with disabilities are more likely to smoke, be overweight or obese, and be physically inactive than individuals who are not disabled.<sup>1,5</sup> In childhood, people with certain disabling conditions, such as spina bifida and hydrocephalous, might receive frequent radiographs, which raises the risk for developing cancer as adults.<sup>6</sup> Furthermore, people with certain disabilities exhibit signs of premature ageing.<sup>1,7</sup> For example, people with certain types of intellectual disability or schizophrenia can have more inflammation

and oxidative stress than those without these conditions.<sup>8,9</sup> Individuals with schizophrenia or neurodegenerative disorders also exhibit shortened telomere lengths.<sup>9,10</sup> Risk factors for cancer can be complex. For example, some women with an intellectual disability have low oestrogen concentrations that probably protect them from developing breast cancer; however, coexisting hypogonadism, nulliparity, and obesity heighten risks of breast cancer.<sup>11</sup> Preliminary evidence suggests that people with disabilities might have higher rates of certain cancers (ie, breast, cervical, colorectal, and prostate cancers and non-Hodgkin lymphoma) than people without disabilities, even after controlling for various risk factors (eg, age, race, ethnicity, socioeconomic status, smoking status, and body-mass index).<sup>12,13</sup>

When people with disabilities do develop cancer, the scientific evidence base for making treatment decisions is often insufficient. Randomised clinical trials routinely exclude people with disabilities.<sup>14</sup> Even in observational and epidemiological studies, data for people with disabilities are rarely available.<sup>15,16</sup> Data from administering health-care services, such as diagnosis codes, provide little information about disabilities.<sup>16</sup> Insights about disability disparities, including in cancer-related care, therefore often come primarily from population-based surveys. However, cultural, and other factors (eg, gender-based roles and expectations) affect the willingness of survey participants to self-report a disability or identify as disabled,<sup>13</sup> raising questions about accuracy across population subgroups (eg, by race, ethnicity, and socioeconomic status). Survey design must accommodate people with different disability types (eg, US surveys routinely underrepresent individuals with intellectual disability).<sup>17,18</sup> Since 2000, interest in examining health-care disparities for people with disabilities has grown. In the context of disabilities, breast cancer and cervical cancer screening services have been extensively studied primarily with surveys and qualitative interview research.<sup>19,20</sup> Much less is known about cancer screening services for men with disabilities than for women or about cancer diagnosis, treatments, or outcomes for all people with disabilities.<sup>19</sup>

### Disparities in cancer screening

Articles about cancer screening and disability are primarily concerned with breast or cervical cancer screening, with some publications also addressing colorectal cancer screening.<sup>19,20</sup> Most articles identify a significant reduction in the use of breast cancer screening and cervical screening among people with disabilities, with less consistent findings for colorectal cancer screening. The extent of disparities generally varies by disability type and severity, sociodemographic factors, and screening service. Important differences across countries exist, although the major barriers identified for cancer screening for people with disabilities appear to be largely similar worldwide.

For example, data from 2010–18, before accounting for sociodemographic characteristics, showed that 83·0% of US women without disabilities aged 30 years or older reported having a mammogram in the past 2 years, compared with 77·1% of women with chronic mobility limitations and 71·4% of women with complex activity limitations; 81·0% of women aged 18 years or older without disabilities reported having cervical screening within the previous 3 years, compared with 67·6% of women with chronic mobility limitations, and 72·5% of women with complex activity limitations.<sup>13</sup> In comparison, in South Korea in 2015, age-standardised breast cancer screening rates were 60·1% for women without disabilities and 53·7% for women with any disability,<sup>21</sup> and cervical cancer screening rates were 53·5% for women without disabilities versus 42·1% for women with disabilities.<sup>22</sup> Studies comparing colorectal screening rates for people with and without disabilities are contradictory, showing disparities<sup>23,24</sup> or higher screening rates for people with disability.<sup>25,26</sup> In 2013, colorectal cancer screening rates in the USA for people aged 50–75 years were 57·0% for individuals without disabilities but 61·8% for people with disabilities.<sup>26</sup> Disparities for colorectal screening were also not observed in South Korea: 33·9% of people without disability received colorectal cancer screening in 2015 compared with 33·4% for people with any disability.<sup>27</sup> Across countries, people with disabilities typically have more frequent physician visits than people without disabilities, and these more regular interactions are thought to contribute to more screening for colorectal cancer for disabled people.<sup>28</sup>

Studies across countries, disability types, and screening services suggest that certain sociodemographic and health characteristics are often highly associated with cancer screening for people with disabilities, although associations vary depending on the context. Age, race, ethnicity, education, marital status, income, employment, health insurance, financial coverage for screening services, geography (urban vs rural), and chronic comorbid conditions are frequently associated with obtaining cancer screening.<sup>19,20,28,29</sup> However, whether significant associations are positive or negative can vary across countries on the basis of factors such as health insurance, cancer-screening funding programmes, and other interventions that affect the accessibility of screening. For example, US women who have a disability and live in rural regions are less likely to receive breast cancer or cervical cancer screening than women living in both urban and rural areas who are not disabled or women who are disabled and live in urban regions.<sup>28,30</sup> By contrast, in Chile<sup>31</sup> and Taiwan,<sup>32</sup> which have prioritised outreach to rural areas, disabled women in rural areas are more likely to have cervical cancer screening than disabled women in urban areas.

Screening disparities generally vary by the severity and type of disability.<sup>22,27,33–36</sup> Disparities in cancer screening—again, primarily breast cancer or cervical screening—

typically widen with the severity of the disability, although findings are inconsistent.<sup>28,37,38</sup> In one US study, women with any mental disorder received breast cancer screening significantly less often than women without mental disorders, with the severity of the mental disorder strongly affecting this overall disparity. However, although severity contributed to lower breast cancer screening rates for women with mood or anxiety disorders, severity played no role for women with psychotic, alcohol, or substance use disorders.<sup>39</sup> In Taiwan, women with mental disorders were also less likely than women without mental disorders to receive breast cancer screening, and screening rates decreased as mental disorder severity worsened.<sup>40</sup> In South Korea, age-standardised breast cancer<sup>21</sup> and cervical cancer<sup>22</sup> screening rates were significantly lower for women with autism, an intellectual disability, brain injury, or mental disorders. In Northern Ireland, after accounting for sociodemographic characteristics, mobility or dexterity difficulties were the only disability type associated with disparities in breast cancer screening.<sup>35</sup>

Similar barriers to cancer screening have been identified for disabled people across countries (panel 1). A patient might not have treatment due to their inadequate knowledge, personal beliefs about risks and benefits of screening, competing health priorities, time constraints, and logistical challenges.<sup>19,38</sup> Absence of transportation makes reaching screening services difficult. Common barriers include physical barriers at health-care facilities, such as no ramps and inaccessible examination rooms and equipment, including examination tables and breast cancer screening machines.<sup>28,38,41,42</sup> For breast cancer screening equipment, common challenges include supporting a standing position, difficulties with arm and shoulder positioning, and accommodating seated people.<sup>42-44</sup> When people with a disability arrive for screening, staff are often inadequately prepared to accommodate their needs.<sup>41</sup> Wheelchair users are routinely examined in their wheelchairs rather than being transferred onto examination tables.<sup>44-46</sup> Previous negative experiences in obtaining health care frequently lead to avoidance of cancer screening.<sup>19,45</sup>

The attitude of health-care professionals also imposes barriers, which is recognised internationally. Beyond the specific context of cancer care, physicians often have stigmatised views of disability, as do other members of society.<sup>41,45,47,48</sup> One survey of US physicians found that 82.4% consider the quality of life of people with a significant disability as worse than that of other people.<sup>49</sup> Physicians' failure to recommend screening services is frequently blamed for low cancer screening among people with disabilities. In South Korea, conscious or unconscious ableist attitudes might contribute to perceptions that active cancer surveillance is not worthwhile for people with disability.<sup>33</sup> Some physicians erroneously view patients with disabilities as sexually inactive and therefore at low risk of human

papillomavirus, and thereby justify not recommending cervical cancer screening.<sup>32</sup>

Some disabilities raise specific concerns for cancer screening. For instance, studies show large disparities for cancer screening for people who have an intellectual disability compared with those who do not,<sup>50-53</sup> and the reasons are complex. People with an intellectual disability who live with families generally have lower cancer screening rates than those who live in group homes or other facilities, perhaps because of the policies or preventive care programmes in these types of residential settings.<sup>51,52</sup> A US qualitative study found that some families decline breast cancer screening for their relative who has an intellectual disability, as they are afraid of finding cancer and having to make difficult treatment decisions.<sup>51</sup> Colorectal cancer screening by colonoscopy can be challenging for people with intellectual disabilities and is complicated by digestive motility disorders, constipation, and seizures; in this context, preparation that requires people to drink large volumes of liquids poses hazards.<sup>50</sup> Questions about sedating people who have an intellectual disability for various screening services often arise, although sedation does not always work.<sup>52</sup> Sedation is also used in other disability contexts, such as performing cervical cancer screening for women with cerebral palsy or women with a high spinal cord injury who are at risk of autonomic dysreflexia.<sup>54</sup> New approaches could reduce cervical cancer screening risks, such as less invasive testing for human papillomavirus before proceeding to speculum examinations.<sup>54</sup>

### Making cancer diagnoses in people with disabilities

Disparities in cancer screening rates raise concerns about the process and timeliness of cancer diagnoses for people with disabilities. Inaccessible medical equipment, ranging from examination tables to imaging technologies, can delay testing to confirm cancer diagnoses.<sup>19,42,44,55,56</sup> For example, one man with a spinal cord injury believes that delays in diagnosing his Hodgkin lymphoma, which presented with enlarged lymph nodes in his groin, were partly caused by his physician always examining him seated in his wheelchair.<sup>48</sup> Primary care physicians might not make appropriate referrals to specialists to evaluate new signs and symptoms for patients who have a disability.<sup>19</sup> In another example, a woman with a spinal cord injury began having autonomic dysreflexia more often, which her primary care physician attributed to her injury.<sup>48</sup> The woman independently consulted her physiatrist who recommended further evaluation that diagnosed uterine cancer. Despite these stories, quantitative evidence does not document the widespread and systematic delays in cancer diagnoses for people with disabilities.<sup>19</sup>

Apart from these screening and access considerations, other factors can affect the timeliness of diagnosing cancer for people with disabilities. In the early 1980s, in

**Panel 1: Examples of impediments to accessing services for people with disabilities and recommendations to health-care professionals and practices for improving access**

**Recommendations for when clinicians do not understand their legal obligations to ensure accessible and equitable care for people with disabilities and physicians do not recommend routine services (eg, cancer screening) to people with disabilities:**

- Become familiar with local legal requirements about ensuring accessible care for people with disabilities
- Review and modify policies in practice settings to ensure equitable care for people with disabilities
- Train clinicians and other staff in their legal responsibilities and how to provide accessible and equitable care to people with disabilities
- Train clinicians and other staff in providing reasonable accommodations to ensure accessible care

**Recommendations for when there are potential disadvantages in social determinants of health, especially not having adequate health insurance and transportation:**

- Involve social work or resource specialists to ensure that patients have access to available supports to address: not having health insurance or resources to cover health-care costs; transportation barriers; low health literacy, inadequate knowledge of risks and benefits (eg, of cancer screening), and difficulties navigating the health-care delivery system; and difficulties exacerbated by rural location

**Recommendations for when there are impediments to physical access to medical diagnostic equipment and other facilities for patients with physical disabilities:**

- Height-adjustable examination tables, accessible stirrups for cervical screening and pelvic examinations
- Wheelchair-accessible weight scales
- Accessible breast cancer screening equipment
- Accessible diagnostic-imaging equipment
- Accessible radiotherapy tables and straps for positioning patients

- Accessible transfer devices
- Personal assistance with positioning and dressing and undressing as preferred by the patient

**Recommendations to overcome ineffective communication with patients with vision impairments, hearing impairments, or both:**

- Ensure patients with vision impairments receive written materials in an accessible format
- Sighted guide to navigate clinical settings and verbally describe settings as preferred by the patient
- Accommodate qualified service animals
- In person or remote sign language interpreter, communication access real-time transcription reporter, or voice amplification device as preferred by the patient
- Masks with clear windows for lip reading and interpreting facial expressions
- Closed caption, audio-described video educational materials

**Recommendations to overcome ineffective communication in the context of patients with comprehension difficulties, mental disorders, or intellectual disabilities:**

- Understand and aim to meet the communication needs and preferences of individual patients
- Schedule extra time for the patients' visits
- Use pictorial representations, models or dolls, and simple language
- Introduce the patient to the care setting and demonstrate the procedure (eg, breast cancer screening)
- Involve a trusted caregiver after assessing their trustworthiness to ensure that individuals who are abusing the patient either emotionally, physically, or in both ways are not involved in providing their care or making care decisions

the context of intellectual disability, and, later, mental disorders, researchers identified the erroneous attribution of patients' new signs and symptoms to their underlying disability, termed diagnostic overshadowing.<sup>57</sup> Qualitative interview research in the USA suggests that diagnostic overshadowing might also occur when people with other types of disability present with new indications of cancer, which are incorrectly ascribed to their disabling conditions.<sup>48,55</sup> For example, a young woman with a spinal cord injury lost weight and had severe abdominal pain for 2 years, causing five visits to the emergency department.<sup>48</sup> Each time, physicians diagnosed gastroparesis related to her injury. She finally became so emaciated that physicians had to place a feeding tube with radiographic guidance and identified a mass that was later diagnosed as Hodgkin lymphoma.<sup>48</sup> Another study reviewing US medical records also identified

instances of physicians erroneously attributing cancer signs or symptoms to the patients' underlying disability.<sup>55</sup>

Little is known about how people with a pre-existing disability react when they do get diagnosed with cancer. A qualitative US study interviewed 20 people with mobility disability who subsequently developed cancer; one common theme was feeling less control over their cancer than their disability, although opinions varied.<sup>58</sup> Some believed that the resilience and personal strength they exhibited living with disability helped them to cope with cancer experiences. Before cancer diagnoses, the interviewees who described their resilience and personal strength used self-advocacy to navigate disability-related barriers. After cancer diagnoses, self advocacy, especially with their oncologists (eg, around accessibility, diagnosis, or treatment decisions) came naturally to some.<sup>19,58</sup> Previous negative health-care experiences can affect the

choices that patients with disabilities make about their cancer treatments.<sup>59</sup> A qualitative study of 20 US women with breast cancer and a pre-existing mobility disability found that disentangling the causes for subsequent functional declines was complicated: was worsening function caused by ageing, natural progression of their disabling condition, or the consequences of cancer and its treatment?<sup>56</sup>

### Cancer stage, treatment, and outcomes

Little is known about cancer treatments or outcomes for people with disability worldwide. Physicians can be uncertain of how to treat people with disabilities who develop cancer because of several factors, including the lack of rigorous scientific evidence for treating this heterogeneous population, unfamiliarity with disabilities and complicated disabling conditions, and the patients' clinical presentations (panel 2).<sup>55</sup> Concerns about competing health risks from the disability or ongoing therapies for the disability can complicate cancer treatment decisions. At a minimum, cancer treatment might exacerbate the baseline weakness and fatigue of some disabling conditions.<sup>59</sup>

Oncologists often assess patients' baseline performance status before making chemotherapy recommendations. However, for people with long-term functional impairments, such as individuals with a spinal cord injury that occurred many years ago, standard performance assessments might not accurately capture the patients' chemotherapy risks.<sup>55,59</sup> Specific impairments can affect the patients' treatment decisions. For example, many women with a movement disability use their arms to assist mobility (eg, self-propelling wheelchairs, canes or walkers, or stabilising themselves during transfers). When diagnosed with early-stage breast cancer, concerns about postoperative arm function might motivate these women to choose breast-conserving surgery over mastectomy.<sup>56</sup> Postoperative arm complications from mastectomy, such as lymphoedema, could seriously impair their ability to do activities of daily living. Weight changes from some treatments, such as hormonal therapy, could affect movement disabilities or wheelchair seating. In various cancer settings, treatments that cause urinary or bowel incontinence raise concerns about skin integrity for people with a substantial mobility disability. Complete care, therefore, must consider supporting the patients' activities of daily living at home, either by ensuring that informal caregivers (family or friends) can provide this assistance or by arranging for paid personal assistance services.<sup>56</sup> However, home-based needs are not always addressed, leaving patients with a disability—especially those who live alone—to cope with cancer treatment in sometimes unsafe, exhausting conditions.<sup>56</sup> Patients who are nonverbal are of particular concern, especially when they cannot identify or describe potentially dangerous cancer treatment side-effects.<sup>51</sup>

#### Panel 2: Examples of barriers to cancer-related care for people with disabilities and recommendations for improving care

##### Lack of evidence for making treatment decisions

- Include people with disabilities in clinical trials
- Include disability status when collecting the routine data that are used for observational studies
- Accommodate communication disabilities and ensure inclusion of people across disability types in health surveys

##### Ableist attitudes among health-care professionals

- Recognise and address implicit and explicit biases and discriminatory attitudes among health-care professionals concerning people with disabilities
- Recognise that people with disabilities experience health and health-care disparities

##### Erroneous assumptions among health-care professionals about people with disabilities

- Do not make assumptions about the values or preferences of people with disabilities; recognize that they value and find enjoyment in their lives similar to people without disabilities
- Recognise that people with disabilities might know more about their underlying disabling condition than do the clinicians providing cancer care
- Involve people with disabilities in collaborative care and shared decision making

##### Inadequate knowledge about the disabling condition

- Seek information from patients about their daily lives, performance of activities of daily living, and daily management of their disabling condition
- Consult or work collaboratively with specialists providing care for the patient's disabling condition

##### Diagnostic overshadowing

- Do not assume that new signs and symptoms relate to the underlying disabling condition
- Perform appropriate diagnostic evaluations of new signs and symptoms to accurately identify cause

##### Failure to anticipate functional implications of cancer treatment

- Consult with patients and rehabilitation specialists or rehabilitation therapists when recommending cancer treatments to proactively identify strategies for preventing or mitigating complications
- Assist in organising home-based supports for patients with disabilities when cancer treatment affects their performance of activities of daily living

The accessibility of medical equipment, such as examination tables, radiotherapy tables, infusion chairs, and weight scales, also requires attention (panel 1). Inaccessible equipment can result in failure to do complete physical examinations and compromise care quality.<sup>42,44,55,56</sup> For instance, the oncologist of a woman with a spinal cord injury lifted her out of her wheelchair and held her in his arms on the clinic's weight scale to assess her weight to establish the dose for breast cancer chemotherapy, as the scale was not wheelchair accessible.<sup>44</sup> In another example, radiotherapy technicians placed a Velcro strap around the waist of a woman with cerebral palsy to position her for breast cancer treatment, but they did not have straps to restrain her arms, which made dyskinetic movements because of her disability.



Technicians then used masking tape to affix her arms to the table during every radiotherapy session.<sup>44</sup>

Publications about cancer treatments for people with pre-existing disabilities are scarce. It was found that Dutch people with probable new diagnoses of lung, cervical, colon, and female breast cancer in 2012 and an intellectual disability had significantly fewer hospital claims than those without intellectual disabilities in the following 3 years.<sup>60</sup> This disparity suggested that people with intellectual disabilities received less treatment than people without intellectual disabilities. A 2017 survey of newly diagnosed patients with breast cancer at 86 German hospitals found that 13% had a pre-existing disability, which was most often a physical impairment.<sup>61</sup> Compared with patients who did not have a disability, individuals with physical impairments were less likely to receive breast-conserving surgery (odds ratio [OR] 0·58; 95% CI 0·44–0·77) and more likely to undergo mastectomy without reconstruction (OR 1·96; 95% CI 1·42–2·68).<sup>61</sup> Among patients with disabilities, 69% reported barrier-free use of medical equipment and 68% said that doctors and nurses met their disability-related needs. A study across 83 German breast cancer centres surveyed patients who had undergone breast cancer surgery in 2014, about whether they had a pre-existing disability and, if so, to what extent.<sup>62</sup> Among 4194 respondents, 780 (18·6%) reported a physical disability. After accounting for socioeconomic status and age, no differences were found in breast cancer stage at diagnosis for patients with or without a physical disability. Controlling for factors, including disability extent and cancer stage, the researchers found that a pre-existing physical disability was associated with lower rates of breast-conserving surgery than for patients without a physical disability, although effect sizes were small.<sup>62</sup> The reason why women who have disabilities receive less breast-conserving surgery is probably multifactorial. This question relates to women with early stage breast cancer. Potential explanations include the women's personal preferences, anticipated difficulties in accessing and undergoing postoperative radiation therapy because of their disability, and ableist attitudes among the surgeons who are recommending treatment options and might not suggest breast-conserving surgery to women with disabilities.

A series of US studies analysed 1988–99 data from the Surveillance, Epidemiology, and End Results cancer registry merged with claims data from the Medicare insurance programme, which covers people aged 65 years and older, and individuals aged 21–64 years who qualify because of a disability.<sup>63–66</sup> Using this administrative definition of disability, the researchers focused on people aged 21–64 years. Considering breast, lung, colorectal, and prostate cancers, they found that, compared with people without disabilities, people with disabilities were diagnosed at earlier stages for lung and prostate cancers and at similar stages for breast or

colorectal cancers.<sup>64</sup> The researchers attributed this seemingly counterintuitive finding to the fact that, by their definition, all people identified as disabled in their data had health insurance (Medicare) and, thus, financial access to care, whereas people younger than 65 years not considered disabled (ie, without Medicare) had high rates of being uninsured. For all four types of cancer, people with a disability had higher rates of all-cause mortality than people without a disability, and higher rates of cancer-specific mortality for breast and colorectal cancers.<sup>64</sup>

Additional in-depth analyses of this data set studied breast cancer<sup>63,65</sup> and stage I non-small-cell lung cancer.<sup>66</sup> After adjusting for sociodemographic characteristics and the cancer attributes available from the Surveillance, Epidemiology, and End Results cancer registry, it was found that women who had a disability had lower relative risks of obtaining breast-conserving surgery (OR 0·80; 95% CI 0·76–0·84) than had women who did not have a disability.<sup>63</sup> Among those undergoing breast-conserving surgery, women with disabilities had lower adjusted relative risks of radiotherapy (OR 0·83; 95% CI 0·77–0·90) and axillary node dissection (0·81; 0·74–0·90) than women without disabilities.<sup>63</sup> Using data on disability entitlement from the Social Security Administration, Iezzoni and colleagues<sup>65</sup> further divided the sample of disabled women with breast cancer by their disability: mental disorders, neurological conditions, circulatory or respiratory conditions, and musculoskeletal disorders. For early stage breast cancer, women with mental disorders or neurological conditions were much less likely to have breast-conserving surgery than were women with cardiorespiratory or musculoskeletal disorders. Analyses of stage I first primary non-small-cell lung cancer found much lower rates of surgery among people with disabilities (68·5%) than in people without disabilities (82·2%).<sup>66</sup> People with disabilities had significantly higher cancer mortality rates than people without disabilities, differences which persisted after adjusting for sociodemographic and tumour characteristics. However, the significantly higher lung cancer mortality rates disappeared after adjusting for differences in surgery.<sup>66</sup>

Publications from South Korea examined the cancer stage, treatment, and outcomes for people with a disability versus people without a disability.<sup>67–71</sup> These analyses identified disabilities from the Korean National Disability Registry, which indicated that only 5·4% of the population was disabled in 2017<sup>67</sup>—just over a third of the rate of disability worldwide,<sup>1</sup> raising questions about the generalisability of the results. Nonetheless, the findings identify several disability disparities. Although people with disabilities were not consistently diagnosed with cancer at later stages, they were significantly more likely to have an unknown stage at diagnosis for gastric,<sup>67</sup> lung,<sup>68</sup> and prostate cancers<sup>69</sup> than age-matched and sex-matched patients who were not disabled. Compared with

this group, people with disabilities were significantly less likely to receive aggressive cancer treatments, such as surgery, radiotherapy, and chemotherapy for lung cancer;<sup>68</sup> chemotherapy and haematopoietic stem-cell transplants for acute myeloid leukemia;<sup>70</sup> and autologous stem-cell transplantation for multiple myeloma.<sup>71</sup> Patients with disabilities had slightly higher cancer-specific mortality than patients who were not disabled for gastric,<sup>67</sup> lung,<sup>68</sup> and prostate cancers,<sup>69</sup> and significantly shorter longevity for acute myeloid leukemia<sup>70</sup> and multiple myeloma.<sup>71</sup>

### Improving cancer care for people with disabilities

Substantial gaps remain in the evidence about cancer care and patients' experiences in the context of disability. Worldwide, this heterogeneous population faces substantial disadvantages in the social determinants of health and barriers posed by physical environments, including within health-care settings, and societal attitudes. Among negative societal views are the ableist attitudes that are exhibited by some physicians and the possibility of diagnostic overshadowing or other factors contributing to delays in cancer diagnoses for people with disabilities. The evidence we do have points to disparities in breast and cervical cancer screening, although these disparities vary by disability type and by socioeconomic factors. Other knowledge gaps include the paucity of rigorous scientific evidence about how to treat cancer in people with disabilities, although the diversity of this population defies easy and consistent answers to therapeutic questions.

Improving cancer care and outcomes for people with disabilities, therefore, starts with the generation of more information about cancer in this population (panel 2). Substantial challenges exist to generating information about disability.<sup>16</sup> Nevertheless, disability data from medical sources can be coded with the International Classification of Functioning, Disability, and Health.<sup>4</sup> WHO has also developed a Model Disability Survey,<sup>72</sup> which is being used to generate population-level information about disability and can potentially be linked to health and health-care data. Enrolling people with disabilities in clinical trials, such as studies of cancer therapies, is essential.<sup>14,15</sup>

Other required improvements include making diagnostic medical equipment and clinical facilities accessible (panel 1).<sup>19,28,42,44,55,56</sup> US standards exist that delineate accessibility requirements for examination tables, weight scales, imaging technologies, and breast cancer screening equipment, although currently there are no regulations that specify how widely available accessible equipment must be.<sup>73</sup> The cost of accessible equipment is concerning; this cost must be weighed against the financial implications of delays in diagnoses and of injuries to patients and clinical staff dealing with inaccessible equipment.

Effective communication between people with disabilities and clinicians is especially important in the context of cancer. Studies repeatedly show inadequate knowledge about the value of cancer screening among disabled people. One study in the USA found that people with a disability report significantly worse communication with health-care professionals than people without a disability, including clinicians who do not understand their care needs and give inadequate attention to emotional concerns.<sup>74</sup> Furthermore, many people with disabilities believe that they know more than their clinicians about their disabling conditions.<sup>19,48</sup> They certainly know more than their clinicians about how disability affects their daily lives. Cancer care clinicians should consult with other specialists who are caring for patients' disabling conditions as appropriate.<sup>48,59</sup> Involving physiatrists and rehabilitation therapists early on in a patients' cancer care could anticipate how therapy might affect patients' functioning and avoid, or mitigate, complications.<sup>59</sup> Clinicians must consider how cancer and its treatments will affect patients' daily functioning in their homes and assist as much as possible in arranging services to support patients at home. Educating cancer clinicians and other staff involved in patient care about disability cultural competence, and implicit and explicit bias relating to disability can also improve care.<sup>59</sup>

To facilitate fully informed, shared decision making in cancer care<sup>75,76</sup> and a collaborative care approach between patients and physicians (where patients are experts about their lives and physicians have technical expertise),<sup>77</sup> clinicians must interact with patients and their families using the communication methods and language appropriate to their needs. For example, US research suggests that deaf sign language users require their preferred communication accommodation to ensure their full participation in shared decision making.<sup>78</sup> Techniques exist to improve accessible communication for people who are blind or have vision impairments.<sup>79</sup> Some populations require accommodations carefully tailored to their individual needs. To improve the breast cancer screening experiences of women with an intellectual disability, for example, it can help to alleviate their fears by showing them the equipment beforehand and describing the procedure.<sup>52</sup> Pictures or videos depicting breast cancer screening are also potentially useful. Relatives or caregivers making cancer treatment decisions for family members who have an intellectual disability might also need extensive education.<sup>51</sup>

### Conclusion

The 2006 UN Convention on the Rights of People with Disabilities recognised the human rights of people with disabilities, including their right to equitable treatment and reasonable accommodations to ensure access to care.<sup>1,2</sup> In the 1990s, more than 40 nations had passed laws prohibiting disability discrimination,<sup>1</sup> and additional laws have been enacted since then. However, as

### Search strategy and selection criteria

References for this Review were identified through searches in October, 2021, of Ovid MEDLINE (database inception to Oct 23, 2021) with no date or language restrictions. The search involved crossing three sets of terms found in article titles or abstracts: (1) disabled person, people, community, or population; (2) disparity, discrimination, or health services accessibility; and (3) neoplasms or cancer and occurrence, incidence, prevention, risk factor, screening, early detection, diagnosis delays, barriers, or treatments. Articles were also identified through searches of the author's files and references from reviewed articles. The final reference list was selected on the basis of relevance for this Review. Most articles on this topic were published after 2005 and came from North America, Europe, and eastern Asia; little was found from South America and Africa.

suggested throughout this Review, people with disabilities still receive inequitable cancer-related care. Physicians might not fully recognise their responsibilities under these laws to make reasonable accommodations and ensure equal access to disabled people.<sup>80</sup> Eliminating these inequities will require health-care professionals to recognise people with disabilities as a population that experiences health-care disparities and ableist attitudes and to listen to them in making accommodation decisions.<sup>19,41,59</sup> With many people with disabilities now living into middle and older ages, cancer prevalence in this heterogeneous population will rise. Providing equitable cancer care to people with disabilities will require creative approaches and a sustained commitment, from generating a rigorous scientific evidence base for treating this diverse population to ensuring access for individual patients with specific needs across the spectrum of cancer care.

### Contributors

LII is the sole author of and contributor to this Review. With the assistance of a medical librarian, she searched the literature for relevant publications. She selected the relevant articles, reviewed them, identified themes for this Review, outlined the paper, and drafted and finalised the Review.

### Declaration of interests

I declare no competing interests.

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