

Perspectives of Patients with Pre-existing Mobility Disability on the Process of Diagnosing Their Cancer



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BACKGROUND: Mobility disability is the most common disability among adult Americans, estimated at 13.7% of the US population. Cancer prevalence is higher among people with mobility disability compared with the general population, yet people with disability experience disparities in cancer screening and treatment.

OBJECTIVE: We explored experiences of patients with mobility disability with the process of cancer diagnosis.

DESIGN: Open-ended individual interviews, which reached data saturation. Interviews were transcribed verbatim for conventional content analysis.

PARTICIPANTS: We interviewed 20 participants with pre-existing mobility disability that required the use of an assistive device or assistance with performance of activities of daily living and who were subsequently diagnosed with cancer (excluding melanoma).

KEY RESULTS: Concerns coalesced around five broad categories: inaccessibility of medical diagnostic equipment affecting the process of cancer diagnosis, attitudes of clinical staff about accommodating disability, dismissal of cancer signs/symptoms as emotional responses to chronic health conditions, misattributing cancer signs/symptoms to underlying disability, and attitudes about pursuing legal action for substandard care. Participants provided examples of how erroneous assumptions and potentially biased attitudes among clinicians interfered with the process of their cancer diagnosis, sometimes contributing to an insufficient workup and diagnostic delays.

CONCLUSIONS: Physical and attitudinal barriers affect the process of cancer diagnosis in people with mobility disability. Though people with mobility disability may be clinically complex, clinicians should be aware of the risks of diagnostic overshadowing (i.e., the misattribution of cancer signs/symptoms to underlying disability) and other erroneous assumptions that may affect timeliness of cancer diagnosis and quality of care. Further efforts, including educating clinicians about challenges in caring for persons with disability, should be considered to improve the process of cancer diagnosis for this population.

TRIAL REGISTRATION: N/A

KEY WORDS: cancer; mobility disability; diagnostic overshadowing; disparities.

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INTRODUCTION

Healthy People 2020 called for eliminating barriers to health-care for people with disability, highlighting disparities in their access to cancer screening and other preventive services.¹ Mobility disability is the most common disability among adult Americans, estimated at 13.7% of the US population.² Cancer prevalence is higher among people with mobility disability compared with the general population,³ raising questions about the possible contribution of lower cancer screening rates among people with disability to this disparity.⁴ Most research on disparities in cancer diagnosis among people with mobility disability have utilized large survey databases.^{4–6} However, few studies have explored in-depth the experiences of patients with mobility disability with the process of cancer diagnosis.^{7–11} One such study from the United Kingdom identified broad factors within their healthcare delivery system that might affect the process of diagnosing cancer among people with mobility disability, including physical access barriers, lack of recognition of disability-related needs, and lack of consideration of aspects of living with disability that may affect cancer care (e.g., various required accommodations).⁹

Thus, little information is available about important aspects of cancer care for a population that, despite relatively high rates of cancer,³ nonetheless experiences disparities in screening and barriers to accessing care.^{4, 12} To explore aspects of cancer care contributing to disability disparities, we framed our study around the model of disability adopted by the World Health Organization (WHO) in 2001. This model views disability as “a dynamic interaction between health conditions ... and contextual factors,” including physical and social environments.¹³ As part of a larger mixed-methods study,^{3, 14, 15} we conducted in-depth interviews with people with pre-existing mobility disability subsequently diagnosed with various types of cancer and identified common themes concerning aspects of physical and social environments as they relate to the process of cancer diagnosis. Our findings are especially

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relevant for general internists, who often order or perform evaluations (e.g., screening tests, physical examinations, initial diagnostic studies) that may lead to a cancer diagnosis.

METHODS

The Massachusetts General Hospital (MGH)/Partners Health-care Institutional Review Board (IRB) approved this study. Participants were informed of interview procedures, including audio-recording, and we obtained verbal informed consent. Below we report items consistent with the COnsolidated criteria for REporting Qualitative Research checklist ([supplementary material](#)).

Interview Protocol

Drawing upon the literature and previous studies, we designed an open-ended interview protocol (see [supplementary material](#)) to examine the cancer experiences of people with mobility disability. The protocol contained modules, including general medical and social history; disability history, such as underlying diagnosis, duration, and use of assistive devices; cancer history, such as symptoms, diagnostic tests, treatment decisions, and overall outcomes; and recommendations for other patients. We intended the interview to take up to 2 h. We treated the first three interviews as pilot tests; the protocol required no changes following these interviews.

Participant Recruitment

We aimed to recruit 20 adult participants who met the following eligibility criteria: 21 to 72 years of age at the time of cancer diagnosis; mobility disability requiring the use of an assistive device and/or assistance performing activities of daily living; disability duration for at least 1 year preceding cancer diagnosis; no prior cancer history; and exclusion of skin cancers, including melanoma. We recruited a convenience sample of participants through posting information about the study on social networks, including local and national disability advocacy organizations, support groups for people living with specific medical conditions (e.g., spinal cord injury, post-polio syndrome, multiple sclerosis, Parkinson's disease, cerebral palsy, Friederich's ataxia), cancer advocacy organizations and support groups, social media recruitment (e.g., Facebook, Reddit, online forums), and the Partners HealthCare Rally research recruitment website. Potential participants had to contact us to express interest in the study.

Eleven individuals who contacted us did not meet eligibility criteria (mostly because they had disability but no history of cancer). We scheduled all eligible participants for an interview; all scheduled participants provided consent and completed the interview (i.e., no eligible participants dropped out). While screening potential participants, we did not ask how

participants learned about our study. We did not confirm self-reports about mobility disability or cancer histories (e.g., through medical record reviews), instead relying upon the veracity of the interview candidates' statements.

Interview Procedures

All interviews were conducted via telephone by L.I.I. (MD, MSc), a woman and professor of medicine and health policy researcher, with extensive experience conducting in-depth, open-ended research interviews with participants on various disability topics. The moderator and participants did not have a relationship prior to study commencement, and participants were not informed of the research goals beyond learning about their experiences with cancer and disability. The research team did not report biases that may have influenced the study's outcomes.

The audio-recorded interviews averaged 57 min; only the participant and interviewer were present for the duration of each interview. Field notes were not taken during the interview. A commercial transcription service provided verbatim transcripts of the audio-recordings. We did not conduct repeat interviews and did not send interview transcripts to participants (i.e., they did not provide feedback). We mailed \$50 gift cards to participants in thanks for their time. N.A. compared interview audio files to transcripts and corrected minor transcription errors.

Analysis

Using a consensus-driven qualitative process,¹⁶ N.A. (research assistant) and L.I.I. (interviewer/principal investigator) analyzed the interview transcripts, with face validation of findings by A.E.J. (oncologist co-investigator). The research team employed conventional content analysis,¹⁷ a qualitative descriptive method^{18, 19} that draws explicitly from data without overinterpretation of results. We used an iterative process, discussing and identifying themes, and a consensus-driven process to confirm themes and their relevance to clinical practice; we did not use qualitative analysis software or specifically code texts. We analyzed transcripts as the interviews were completed, and we reached data saturation for the broad general themes with the completion of the 20 interviews.

RESULTS

Table 1 presents demographic information about the 20 participants. Their mean (SD) age was 59.6 (12.8) years, and they lived in 11 different states. Participants had nine different cancer types, and eight different underlying disabling conditions. Five major themes describing diagnostic experiences for persons with pre-existing mobility disability emerged from the data. Below, we present these themes with verbatim quotations to exemplify key

points. We sometimes indicate counts of observations not to suggest that our findings are quantifiable but to avoid frequently using vague terms, such as “many,” “most,” or “often.”

Inaccessibility of Medical Diagnostic Equipment Affects Process of Cancer Diagnosis

Inaccessible medical diagnostic equipment interfered with routine evaluations. Fifteen participants indicated that they were not routinely transferred to examination tables, and 11 reported that they were not routinely weighed. Some voiced concerns about substandard quality of care and questioned whether failure to receive complete physical examinations delayed their diagnostic workup.

“They got a six-foot-high table that regular people sit on,” said one participant with spinal cord injury (SCI), “but I can’t jump on, because that’s like me climbing Mount Everest ... I have to be ... observed or diagnosed sitting in the [wheel]-chair. To me, it’s not professional.” This participant noted that being examined seated in his wheelchair is the norm during office visits, and he believed this contributed to delaying his Hodgkin lymphoma diagnosis:

I had a lot of pain in my groin. ... I went to the doctor, and it was the size of about a bean... They don’t put me on a table. ... [The doctor] stuck his finger [into the patient’s groin, with the patient seated], and he goes, ‘Oh, that’s an infection. ... Take these antibiotics for seven days.’...The problem is, after the seven days, that bean turned into a little tennis ball. ... Three weeks later, the golf ball had grown into the size of a grapefruit. Participants raised concerns about how inaccessible equipment might affect their quality of care. One participant with double amputations stated that doctors had offered to examine her in her wheelchair, but she “really wasn’t comfortable with [that].” The participant wanted to be in the best position for the physician to perform her exam, “rather than trying to accommodate me on my chair.” Another participant diagnosed with prostate cancer, who cannot climb onto an examination table, raised concerns about an inadequate physical exam: “The rectal exam was just kind of standing up and leaning over the table.” He described his prostate biopsy being performed in a similar fashion.

Inaccessible equipment generated other concerns, including physicians asking patients to provide their own assistance to transfer onto examination tables. “This is not okay,” said a participant with cerebral palsy. “I’ve heard things in the background, ‘Did she come with someone? Can someone put her on the table?’ I would chime in, ‘I don’t have to come with anybody. You have to have the ability to help me get on the table.’”

Participants also highlighted concerns with inaccessible weight scales. “I don’t think I’ve ever been weighed at a

doctor’s appointment,” said a woman with cerebral palsy. “They always just ask me. The only place I’ve ever gotten consistently weighed the right way is when I joined Weight Watchers.” Another participant indicated that he has his weight measured when he visits the veterinarian with his dog: “Every time I bring my dog [for a checkup], I weigh the dog, and then I weigh me.” Lacking an accessible weight scale “was a huge factor in why I was misdiagnosed,” said one woman. She added:

I was going to the doctor, and I got down to 67 pounds ... and I’m 5’11”... When I would go to the doctor, they wouldn’t weigh me, but they could see that I was very thin. But I think if they would have weighed me, maybe they would be like, ‘Oh, wow. We need to get this girl in to the doctor or hospital right now. Get her tested out. See if there’s something bigger going on.’ Because there was. The inaccessibility of other medical diagnostic equipment also posed challenges for diagnostic workups. “MRIs, and the CAT scans, and the bone scans ... They’re kind of hard to get onto,” said one participant. “Even when you go to the hospital,” said another participant, “when you got to do an ultrasound or a CAT scan, I can’t climb on that thing. It’s too high ... PET scans, none of that.” Another participant who needed a standing breast biopsy recounted:

“You are required to stand so that you can be very still and not move, which are issues for me. But in addition to that, I’m a bigger girl. ... I was over the ‘weight limit’ for the chair that they allegedly use [for breast biopsies] when people can’t sit down. And I’m like, ‘This is not an amusement park ground.’” The participant observed that the hospital “could do a better job of dealing with people’s bodies as they see them, whether it’s a mobility issue or if it’s a size either too little, too short, too tall.”

Attitudes of Clinical Staff About Accommodating Disability

Participants observed that clinical staff have complex attitudes about providing disability accommodations. “Doctors are not very accommodating with disability,” stated one participant. Another participant observed, “I often find that when they just don’t listen to you, don’t respect you, and then that makes everything hard.” She added:

I can remember one technician who was rough... But once I got positioned and if they listened to me about what they needed to do to get me comfortable, then I can lie and do a test, an MRI for a long time or, certainly, a CAT scan ... I think the hardest time for me is that, really, when people just don’t believe you.

Table 1 Demographic Characteristics N=20

Characteristic	
Age at diagnosis, mean (SD) years	59.6 (12.8)
Gender, <i>n</i>	
Male	8
Female	12
Race, <i>n</i>	
White	18
Non-White	2
Hispanic ethnicity, <i>n</i>	1
Education, <i>n</i>	
Less than high school	1
High school or GED	3
Some college	3
Bachelor's degree or higher	13
Marital/partner status, <i>n</i>	
Married	11
Partnered	1
Divorced	4
Widowed	1
Single	3
Health insurance, <i>n</i>	
Medicaid	2
Medicare	6
Private	8
Other*	3
None	1
Underlying disabling condition	
Spinal cord injury	5
Polio	5
Multiple sclerosis	2
Other	8
Cancer type	
Prostate cancer	6
Colorectal cancer	2
Ovarian cancer	3
Non-Hodgkin lymphoma	2
Breast cancer	2
Thyroid cancer	2
Other	3
Family history of their cancer type, <i>n</i>	
Yes	4
No	5
Not reported	11

*History of other combinations of insurance (e.g., private, Medicaid, and/or Medicare)

They don't believe you need to have what you need to have. I used to tell the MRI people, 'If you get me settled on the table, I will be yours for however long you want. But if I'm not settled well on the table and I have some spasticity in my foot or whatever, then I'm going to be really hard to test.' Participants expressed frustration about the inability to accommodate disability. "I feel like they should care a little bit more because of the disability." Another participant concurred: "I really think just because of the barriers to healthcare that there's got to be a higher instance of cancer among people with significant physical disabilities." She was surprised at the lack of preparedness in clinical settings to accommodate disability.

Dismissal of Cancer Signs/Symptoms as Emotional Responses to Chronic Health Conditions

Participants suggested that physicians did not always take their cancer signs or symptoms seriously, often because of erroneous assumptions that they were caused by emotional responses

to chronic health conditions rather than valid medical concerns. "When I was younger, my 20s, my 30s," one woman recalled, "before I had developed my identity as a person with a disability ... it was like, 'No, I'm not depressed. I feel this. This is real.'" A woman with difficulty ambulating due to an orthopedic condition, later diagnosed with ovarian cancer, had experienced abdominal pain and fatigue for 2 years, but her clinicians told her, "'Oh, because of 9/11, you're just depressed.' And I said to them, 'It is not depression. Something is very wrong.'" Another woman asserted it took 2 years to diagnose her colon cancer: "Everyday it was like, 'Well you need to go see pain management,' which is basically, 'You need to go see the psychologist.'" She added:

I got a phone call from a senior resident who said to me over the phone... 'There's something that's seriously wrong with you that you come in and call us as much as you do.' And I said, 'Because nobody should go to the bathroom every hour to two hours with diarrhea.' ... The chief of GI did the colonoscopy at [MAJOR ACADEMIC MEDICAL CENTER]. She said, 'There's nothing wrong. You're complaining for nothing. This is your fifth colonoscopy. There's nothing wrong with you.' Three days later I get a phone call back that it's cancer.

Misattributing Cancer Signs/Symptoms to Underlying Disability

Ten participants appeared to have their cancer diagnosed on routine screening or routine follow-up tests performed to assess their symptoms. However, the other half of the participants experienced diagnostic delays resulting from the erroneous attribution of cancer signs/symptoms to underlying disability. In some instances, participants themselves delayed seeking care because they thought their symptoms were disability-related; in other instances, the participants' clinicians made these erroneous assumptions. In some situations, these delays had severe consequences.

A man with paralysis from neuromyelitis optica, who had an indwelling suprapubic catheter, indicated that developing urinary tract infections (UTIs) was common for him. When he began experiencing more UTIs, he thought, "maybe the catheter got plugged up." He suggested that misattribution of the UTIs may have delayed his prostate cancer diagnosis: "If I had not had all these UTIs, the urologist would have done the MRI ... it probably would've been found maybe a year earlier." Another man with prostate cancer had attributed his cancer symptoms to multiple sclerosis: "I always think it was mostly the MS was the problem with the bladder because the bladder symptoms are about the same since, for the last 10 or 15 years for me." A woman with difficulty ambulating said, "Well, I had symptoms, but I didn't associate it with ovarian cancer. I thought I was just having pain because maybe I was constipated."

Sometimes clinicians attribute cancer symptoms to the participants' underlying disability. "For two years ... I was just losing weight," said a patient with SCI. "They diagnosed me with gastroparesis. They said that my stomach, because of the [spinal cord] injury, was digesting food slower, and that that was the issue." The participant had visited the emergency room five times across 2 years. The gastroparesis diagnosis stuck, although, "They never even did any testing to even say that it was gastroparesis." Eventually, with life-threatening weight loss, the participant needed a feeding tube inserted. "So, they gave me an X-ray to place it," said the participant, "and that's finally when they found a mass that was right next to my lung. And it was stage II Hodgkin's lymphoma... I didn't even have gastroparesis."

One woman with SCI experienced increased episodes of autonomic dysreflexia. Her primary care physician attributed the dysreflexia to her SCI but did not recommend further investigation of its increased frequency, telling the participant that testing would be intrusive. However, the participant's rehabilitation specialist was alarmed by the increased dysreflexia, and a subsequent workup revealed uterine cancer.

A woman with cerebral palsy experienced difficulty swallowing, a recognized complication of her disability. She later developed a cough and was given cough suppressant. She was concerned about seeking follow-up, "because they attribute it to my disability, and they don't really pay attention." She was subsequently diagnosed with thyroid cancer, which she believes contributed to her swallowing difficulties and cough.

Participants warned about the dangers of misattributing cancer signs/symptoms to underlying disability. "Not everything is polio related," said a participant with post-polio syndrome. "So, you have to be careful, right?" Another participant observed, "It's always easy to blame everything on the MS. So, you have to think very carefully about what's going on and what's not going on."

Attitudes About Pursuing Legal Action for Substandard Care

Some participants raised questions about pursuing malpractice claims for substandard care. "I've never even gotten an apology," said one participant who experienced a delayed diagnosis for 2 years because her cancer symptoms were misattributed to SCI. "I never even heard from that doctor." She had considered suing about her missed diagnosis, but "I've gone through a lawsuit before, and I'm like, 'No.' It makes life more stressful." Another participant suggested that clinicians are not worried about lawsuits from people with disability. "They don't care," said another participant with SCI. "You know why they don't care? Because the odds of that happening is few and far between. First of all, litigation costs are a lot of money for people with disability." The participant thought that clinicians are reluctant to transfer him onto an exam table because of liability concerns: "The office don't want to

take liability, lifting me, because they think that if I fall, that I'm going to sue them. ... So, they just leave me in the chair."

Participants expressed concerns that if they complained, their care would suffer: "The bottom line is, if they don't want to do it, I'm not going to break their arm to do it. ... What kind of treatment am I going to get?" Another participant observed that he is "not a zealot when it comes to accessibility ... All I care about is function over form."

DISCUSSION

Few studies^{7, 8} have explored the experiences of people with mobility disability with the process of cancer diagnosis. We believe that this is the first US-based research study to explore these issues across various cancer types. Our findings about inaccessible medical diagnostic equipment (e.g., exam tables, weight scales, diagnostic imaging equipment) are consistent with prior literature.^{20, 21} Less reported are our findings about how erroneous assumptions and potentially biased attitudes among clinicians might interfere with the process of cancer diagnosis, sometimes contributing to an insufficient workup and diagnostic delays. Table 2 summarizes potential recommendations for addressing concerns raised by each identified theme.

Of note, some interview participants reported that clinicians misattributed physical signs and symptoms of cancer to their underlying, pre-existing mobility disability, a practice called "diagnostic overshadowing" in the context of other types of disability. The concept of diagnostic overshadowing was initially formulated in the setting of intellectual disability. Researchers identified instances where emergency department physicians would erroneously attribute various presenting clinical symptoms of patients with intellectual disability to their disability rather than to their actual medical illnesses.^{22–}

²⁴ In our study, participants suggested that diagnostic overshadowing might also occur for persons with physical disability, as physicians misattributed signs and symptoms of cancer to their underlying disabling condition (e.g., misattributing symptoms of Hodgkin lymphoma to presumed, albeit never proven or even tested, gastroparesis from SCI.)

Participants also described that attitudinal barriers can contribute to misattribution of cancer signs and symptoms to emotional reactions related to living with chronic health conditions. Research on the health experiences of older people supports this finding, suggesting that physical health issues can sometimes be misattributed to undiagnosed depression related to aging.²⁵ Erroneous assumptions about quality of life of people with disability are similarly pervasive in society and may also affect clinician-patient interactions. The disability paradox concept²⁶ describes discordance between positive perceptions of quality of life among people with disability and negative societal perceptions. Disability simulation

Table 2 Themes and Recommendations

Theme	Recommendation
Inaccessibility of medical diagnostic equipment affecting the process of cancer diagnosis	<ul style="list-style-type: none"> • Install accessible medical diagnostic equipment including wheelchair accessible weight scales, height-adjustable exam tables, and/or transfer devices (e.g., Hoyer lift) • For specific equipment requirements, seek guidance from the federal <i>Standards for Accessible Medical Diagnostic Equipment</i> (e.g., height-adjustable exam tables should lower to 17–19 in. above ground to facilitate transfers)
Attitudes of clinical staff about accommodating disability	<ul style="list-style-type: none"> • Develop procedures for appropriate patient positioning (e.g., for MRI or biopsy) • Staff training should include modules on disability cultural competence • Develop policies and procedures for proactively inquiring about patients' accommodation needs to anticipate accessibility difficulties • Train staff in their legal responsibilities for accommodating patients with disability and how decisions about reasonable accommodations are made • Train staff in ergonomic transferring and patient positioning techniques to maximize patients' comfort, reduce risk of injury to clinical staff, and improve technical quality of diagnostic test (e.g., appropriately and comfortably positioned patients have better diagnostic imaging quality)
Dismissal of cancer signs/symptoms as patients' emotional responses to chronic health conditions	<ul style="list-style-type: none"> • Improve staff training about risks of misattributing patients' signs/symptoms to psychological factors • Improve staff training about potentially biased attitudes towards disability (e.g., through taking an online disability implicit association test)
Misattributing cancer signs/symptoms to underlying disability	<ul style="list-style-type: none"> • Train staff about the risks of "diagnostic overshadowing" in the context of pre-existing conditions including mobility disability • Consider consultation with physician experts in disability (e.g., physiatrists)
Attitudes about pursuing legal action for substandard care	<ul style="list-style-type: none"> • Train staff about their responsibilities towards patients under the Americans with Disabilities Act (ADA)

modules, commonly used in educating trainees about disability, may have the unintended effect of amplifying erroneous assumptions that disability causes poor quality of life and mental health. These simulations often generate distress, pity, and negative perceptions about living with disability.^{27, 28} Because cancer, depression, and stress can share similar nonspecific symptoms (e.g., fatigue, weight loss), clinicians' erroneous assumptions about living with disability could possibly affect their clinical assessments.

Nonetheless, participants provided nuanced perspectives on misattribution of cancer symptoms. Participants themselves sometimes assumed that physical signs and symptoms were related to their underlying disability, potentially delaying care. Whether patients can pursue legal action due to diagnostic overshadowing is unclear—only cases where overshadowing caused major delays that harmed the patient and met other criteria as malpractice claims may warrant consideration.²⁹ Inability to obtain routine preventive screening due to inaccessible medical diagnostic equipment and inadequate disability accommodations constitutes violation of the Americans with Disabilities Act (ADA).³⁰ However, as participants recognize, patients may be unlikely to pursue litigation given the time, cost, and stress involved. Under ADA mandates, clinical practices have an obligation to provide disability accommodations.

Challenges examining patients in the absence of accessible medical diagnostic equipment are well-documented in the literature.^{20, 21, 31} However, the direct implications for the process of cancer diagnosis are a novel finding,

with participants providing vivid descriptions that clarified the implications. Transferring patients to exam tables is critical for thorough examinations, as for the participant with non-Hodgkin lymphoma whose initial symptom—a mass in the groin area—was inadequately assessed as he sat in his wheelchair. Unexplained weight loss can also be a nonspecific cancer symptom—as for the interviewee with Hodgkin lymphoma who experienced life-threatening weight loss—suggesting the importance of accessible weight scales. Because the absence of accessible medical diagnostic equipment can lead to substandard care, training from undergraduate through continuing medical education should include modules addressing practice accessibility requirements under the ADA. Federal *Standards for Accessible Medical Diagnostic Equipment* were promulgated in 2017³⁰; practice settings across the US healthcare system should consider implementing these standards.

Participants also described accessibility barriers with more specialized diagnostic procedures, including imaging services (i.e., MRI, CT, PET scans) and biopsies. Appropriate patient positioning is critical for ensuring image quality—inability to accommodate mobility disability can interfere with diagnosis. Furthermore, attitudes of clinical staff about providing accommodations can be just as important as physical accessibility. Patience with transferring and positioning patients and proactively inquiring about accommodation needs can anticipate accessibility difficulties. Nevertheless, broader attitudes and biases towards people with disability³² can interfere with efforts to proactively address access barriers.

Limitations

Our findings have important limitations, notably concerning generalizability to patients with different cancer types and conditions causing mobility disability. Given the opt-in recruitment strategy, we have no information on non-participants (i.e., the number of people who chose not to participate and their reasons). The experiences of people choosing not to participate may differ from those reported here. For example, our finding that most participants experienced physical access barriers and other barriers for cancer diagnosis may potentially reflect recruitment bias (i.e., people dissatisfied with their care might be highly motivated to voice their concerns).

Limitations caused by mobility disability and cancer signs and symptoms can be highly variable, limiting our ability to draw conclusions about specific aspects of diagnosis and treatment across patients. Furthermore, given the diversity of disability and cancer type combinations in our study sample, we cannot compare subgroups of participants based on these characteristics. Nevertheless, our ability to reach data saturation for general themes suggests the salience of these observations to diagnostic experiences. Despite limited generalizability, the findings are transferrable to physician practices more broadly, given that both general internists and oncologists play important roles in the process of cancer diagnosis.

CONCLUSION

We found that participants with pre-existing disability subsequently diagnosed with cancer report physical barriers to healthcare (i.e., inaccessible medical diagnostic equipment), attitudinal barriers among clinical staff (i.e., reluctance to accommodate disability), and the misattribution of signs and symptoms to patients' emotional concerns or underlying disability. Further efforts to improve the process of cancer diagnosis for this sometimes complex population are warranted, including training clinicians about the potential risks of diagnostic overshadowing.

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REFERENCES

- Centers for Disease Control and Prevention. Healthy People 2020 – Disability and Health. Department of Health and Human Services; 2016. <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>.
- Okoro C, Hollis N, Cyrus A, Griffin-Blake S. Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67(32):882-887.
- Iezzoni LI, Rao S, Agaronnik N, El-Jawahri A. Cross-sectional analysis of the associations between four common cancers and disability. *J Natl Compr Cancer Netw*. 2020;18(8):1031-1044.
- Andresen EM, Peterson-Besse JJ, Krahn GL, Walsh ES, Horner-Johnson W, Iezzoni LI. Pap, mammography, and clinical breast examination screening among women with disabilities: a systematic review. *Womens Health Issues*. 2013;23(4):e205-e214.
- Iezzoni LI, Kurtz SG, Rao SR. Trends in colorectal cancer screening over time for persons with and without chronic disability. *Disabil Health J*. 2016;9(3):498-509.
- Iezzoni LI, Kurtz SG, Rao SR. Trends in mammography over time for women with and without chronic disability. *J Womens Health (Larchmt)*. 2015;24(7):593-601.
- Iezzoni LI, Kilbridge K, Park ER. Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments. *Oncol Nurs Forum*. 2010;37(6):711-717.
- Iezzoni LI, Park ER, Kilbridge KL. Implications of mobility impairment on the diagnosis and treatment of breast cancer. *J Women's Heal*. 2011;20(1):45-52.
- Sakellariou D, Anstey S, Gaze S, et al. Barriers to accessing cancer services for adults with physical disabilities in England and Wales: an interview-based study. *BMJ Open*. 2019;9(6):e027555.
- Edwards DJ, Sakellariou D, Anstey S. Barriers to, and facilitators of, access to cancer services and experiences of cancer care for adults with a physical disability: A mixed methods systematic review. *Disabil Health J*. 2020;13(1):100844.
- Volker DL, Becker H, Kang SJ, Kullberg V. A double whammy: health promotion among cancer survivors with preexisting functional limitations. *Oncol Nurs Forum*. 2013;40(1):64-71.
- Gofine M, Mielenz TJ, Vasani S, Lebowitz B. Use of colorectal cancer screening among people with mobility disability. *J Clin Gastroenterol*. 2018;52(9):789-795.
- World Health Organization. International Classification of Functioning, Disability, and Health. Geneva: World Health Organization; 2001.
- Agaronnik ND, Lindvall C, El-Jawahri A, He W, Iezzoni LI. Challenges of developing a natural language processing method with electronic health records to identify persons with chronic mobility disability. *Arch Phys Med Rehabil*. 2020;101(10):1739-1746.
- Agaronnik ND, Lindvall C, El-Jawahri A, He W, Iezzoni LI. Using natural language processing to assess frequency of functional status documentation for patients newly diagnosed with colorectal cancer. *JAMA Oncol*. 2020;6(10):1628-1630.
- Hill CE, Thompson BJ, Williams EN. A guide to conducting consensual qualitative research. *Couns Psychol*. 1997;25(4):517-572.
- Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
- Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Heal*. 2010;33(1):77-84.
- Sandelowski M. Focus on research methods: Whatever happened to qualitative description? *Res Nurs Heal*. 2000;23:334-340.
- Lagu T, Hannon NS, Rothberg MB, et al. Access to subspecialty care for patients with mobility impairment: a survey. *Ann Intern Med*. 2013;158(6):441-446.
- Agaronnik N, Campbell EG, Ressler J, Iezzoni LI. Accessibility of medical diagnostic equipment for patients with disability: Observations from physicians. *Arch Phys Med Rehabil*. 2019;100(11):2032-2038.
- Jones S, Howard L, Thornicroft G. "Diagnostic overshadowing": worse physical health care for people with mental illness. *Acta Psychiatr Scand*. 2008;118(3):169-171.

23. **Happell B, Ewart SB, Bocking J, Platania-Phung C, Stanton R.** "That red flag on your file": misinterpreting physical symptoms as mental illness. *J Clin Nurs.* 2016;25(19-20):2933-2942.
24. **Shefer G, Henderson C, Howard LM, Murray J, Thorncroft G.** Diagnostic overshadowing and other challenges involved in the diagnostic process of patients with mental illness who present in emergency departments with physical symptoms—a qualitative study. *PLoS One.* 2014;9(11):e111682.
25. **Holm AL, Lyberg A, Severinsson E.** Living with stigma: Depressed elderly persons' experiences of physical health problems. *Nurs Res Pract.* 2014;1-8.
26. **Albrecht GL, Devlieger PJ.** The disability paradox: High quality of life against all odds. *Soc Sci Med.* 1999;48(8):977-988.
27. **Nario-Redmond MR, Gospodinov D, Cobb A.** Crip for a day: The unintended negative consequences of disability simulations. *Rehabil Psychol.* 2017;62(3):324-333.
28. **French S.** Simulation exercises in disability awareness training: A critique. *Disabil Handicap Soc.* 1992;7(3):257-266.
29. 22 U.S. Code § 2702. Malpractice protection. <https://www.law.cornell.edu/uscode/text/22/2702>.
30. Architectural and Transportation Barriers Compliance Board. Standards for Accessible Medical Diagnostic Equipment. 36 CFR Part 1195.; 2017.
31. **Story MF, Schwier E, Kailes JI.** Perspectives of patients with disabilities on the accessibility of medical equipment: Examination tables, imaging equipment, medical chairs, and weight scales. *Disabil Health J.* 2009;2(4):169-179.e1.
32. **Agaronnik N, Campbell EG, Ressler J, Iezzoni LI.** Exploring issues relating to disability cultural competence among practicing physicians. *Disabil Health J.* 2019;12(3):403-410.

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