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Experiences of health professionals conducting cancer screening of individuals with intellectual disabilities: A phenomenological study

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ABSTRACT

Background: Cancer, with its increasing incidence and mortality rates, remains one of today's top global public health concerns. People with intellectual disabilities, a vulnerable population group, are at increased risk of developing cancer due to their high prevalence of behavioral risk factors. This study aims to examine the experiences of health professionals who perform cancer screening on individuals with intellectual disabilities.

Method: The research is a phenomenological study. Data were collected from 13 healthcare professionals working in Cancer Early Diagnosis, Screening, and Education Centers between May and August 2025. A semi-structured interview form based on the literature was used to collect data. The data were analyzed using thematic analysis.

Results: Participants' experiences were examined under four themes and eleven subthemes: the meaning of caring for an individual with intellectual disabilities, difficulties experienced, coping with difficulties, and encouragement for cancer screening.

Conclusion: It has been determined that healthcare professionals experience professional satisfaction when providing care to individuals with intellectual disabilities, but at the same time, they face challenges during this process. Healthcare professionals and managers working in screening units should collaborate to restructure services aimed at increasing the participation of individuals with intellectual disabilities in cancer screening programmes.

What this paper adds

- Providing care to individuals with intellectual disabilities contributes to healthcare professionals' satisfaction.
- Lack of knowledge among healthcare professionals about individuals with intellectual disabilities is concerning.
- Services should be restructured to improve access and participation in cancer screening programmes.

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1. Introduction

Cancer remains one of today's most pressing global public health issues, with increasing incidence and mortality rates each year (Raza, 2025). World Health Organisation (WHO) data for 2020 indicates that approximately 10 million cancer-related deaths occurred worldwide, accounting for approximately 16.7% (roughly one in six) of all deaths. (WHO, 2025). The pathogenesis of cancer involves the multifaceted interaction of biological, genetic, behavioural, and environmental factors. Biological risk factors include variables such as age, gender, and ethnicity, while genetic risk factors manifest themselves primarily in the form of specific gsecond-hand smoke, air pollution, ionising radiation, and various chemical agents. Behavioural risk factors include tobacco and alcohol use, physical inactivity, unhealthy diet, consumption of processed foods, obesity, and exposure to ultraviolet radiation (Mbemi et al., 2020; Nguyen et al., 2025). However, the behavioral risk factors mentioned are often not considered solely as individual preferences. It is stated that risk factors are closely related to individuals' capacity to acquire, understand, and use health information. In this context, health literacy is defined as the ability to develop, understand, process, and apply health information in health-related decision-making. It is directly linked to participation in cancer prevention behaviors (Fleary et al., 2019). Low levels of health literacy are associated with behavioral risk factors such as tobacco use, physical inactivity, and insufficient fruit and vegetable consumption (Fernandez et al., 2016); it is also linked to misconceptions about cancer, limited information-seeking behavior, and a perceived lack of control over cancer risks (Kobayashi & Smith, 2016). Moreover, it has been shown that individuals with intellectual disabilities, a vulnerable population group, have a higher risk of developing cancer due to the presence of higher levels of behavioral risk factors (Caton et al., 2012; Hsieh et al., 2014; Reif et al., 2022).

Intellectual disability is a neurodevelopmental disorder that begins during the developmental period. Characterised by limitations in intellectual functions such as problem solving, reasoning, planning, judgement, and learning (DSM, 2013), this disability causes individuals to require support in their social, communication, and interpersonal skills, as well as in carrying out daily living activities (Lee et al., 2021). The need for support is extremely valuable in improving the quality of life of individuals with intellectual disabilities and promoting their integration into society(Sappok et al., 2025). Indeed, due to the barriers faced by these individuals, they are confronted with health inequalities and the risk of premature death. Cancer diagnoses in individuals with intellectual disabilities are often made at a more advanced stage, and this situation, which limits treatment options, leads to high mortality rates (Hansford et al., 2024; Heslop et al., 2022; Mahar et al., 2024), and the risk of cancer-related death in these individuals is 1.5 times higher than in the general population (Cuypers et al., 2022). Although there is no data on cancer incidence in individuals with intellectual disabilities worldwide, epidemiological evidence suggests that people with intellectual disabilities have a higher risk of developing certain cancers (Banda et al., 2024; Liu et al., 2021). For example, a cohort study conducted in Sweden found that the overall cancer incidence among individuals with intellectual disabilities was 58% higher than that of the general population (Liu et al., 2021) This increase was particularly pronounced in cancers of the oesophagus, stomach, small intestine, colon, pancreas, and kidney. These findings indicate that individuals with intellectual disabilities are at higher risk of developing cancer. Therefore, it is crucial to control behavioural risk factors and increase access to cancer screening and early diagnosis services for individuals with intellectual disabilities (Liu et al., 2021). WHO emphasises that early diagnosis of precancerous lesions could prevent 30–50% of cancers and reduce mortality rates (WHO, 2025). In this context, breast, cervical, and colon cancer prevention and screening have been established as a fundamental public health strategy by many countries (EuropeanCommission, 2021a). However, it is noted that screening programmes implemented to protect public health are designed with the general population in mind. Therefore, the specific needs of vulnerable groups may be neglected (Chan et al., 2022). Indeed, intellectual disability affects 1% of the population (American Psychiatric Assosiation, 2024), and women with intellectual disabilities are less likely to participate in cancer screening programmes compared to those without disabilities. (Chan et al., 2022). It is stated that this situation is of vital importance for individuals with intellectual disabilities, who are one of the vulnerable groups facing significant barriers in accessing healthcare services (Golubović et al., 2024).

The findings reveal that cancer screening programs lack sufficient resources and planning to support the participation of individuals with intellectual disabilities in screenings (Kuper & Azizatunnisa', 2025). This finding indicates that existing screening programs need to be restructured to better address the needs of the collaboration of interdisciplinary stakeholders, including public health nurses, oncology nurses, nurses caring for individuals with intellectual disabilities, other healthcare professionals, educators, and policymakers. Given the need to increase the participation of individuals with intellectual disabilities in screening programs, the experiences of healthcare professionals conducting the screenings are thought to be instructive and contribute to strategies that can be implemented to improve the utilization of cancer screening programs (McIlfatrick et al., 2011). A review of the literature reveals that only a limited number of studies examine the perspectives of primary care providers (Breau et al., 2020; Breau et al., 2023) and informal caregivers (Golubović et al., 2024) on cancer screening for individuals with intellectual disabilities. However, no studies have been found that examine the experiences of healthcare professionals who perform cancer screening in individuals with intellectual disabilities. Therefore, this study aims to examine the experiences of healthcare professionals who perform cancer screening for individuals with intellectual disabilities.

2. Methods

2.1. Design

This research is a phenomenological qualitative study aiming to gain an in-depth understanding of the experiences of healthcare professionals who conduct cancer screening for individuals with intellectual disabilities. Phenomenology is an approach that seeks to uncover individuals' experiences of a particular phenomenon and the meanings they attribute to these experiences The research was

conducted using a phenomenological design to reveal the individuals' experiences, perceptions, and the meaning they attributed to their situation (Creswell & Poth, 2016). This research was conducted based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

2.2. Participants

The study population consisted of healthcare professionals working at Cancer Early Diagnosis Screening and Education Centres (KETEM) located in the central districts of XX, XX. The principle of maximum diversity was employed in determining the study sample, which consisted of healthcare professionals who met the study's inclusion criteria. The inclusion criteria for the study were: having worked at KETEM for at least one year, providing care to individuals with intellectual disabilities during cancer screening. In qualitative research, data saturation guides the selection of the sample size (Guest et al., 2006). In this study, data saturation was achieved with 13 participants.

The participants' age ranged between 30 and 50, and the vast majority were university graduates. The participants' occupations included nurses, midwives, doctors, healthcare professionals, and radiology technicians. It was determined that the participants' professional experience ranged from 6 to 29 years, while their length of service at KETEM ranged from 2 to 20 years. Only two healthcare professionals stated that they were aware of individuals with intellectual disabilities who regularly participated in screenings. (Table 1). To ensure maximum data diversity, the study included participants from diverse age groups, educational backgrounds, occupations, and years of work experience (LeCompte & Preissle, 1993).

2.3. Data Collection

The data for the study were collected between May and August 2025 at the Cancer Early Diagnosis Screening and Education Centres (KETEM) located in the central districts of Samsun/Türkiye. The research data were collected through face-to-face interviews conducted in an empty room at the relevant centers, using participant information forms and semi-structured individual interview forms. During the data collection process, an environment was created that allowed participants to feel comfortable and secure. The interviews were conducted within a framework of mutual trust; participants were able to answer questions of their own free will, without any guidance or pressure.

2.3.1. Participant identification information form

The form prepared by the researchers consists of five questions (age, education, occupation, years of work experience, KETEM working year).

2.3.2. Semi-structured individual interview form

Data was collected using a semi-structured interview form prepared by the researchers. The interview form was evaluated by three individuals specialising in qualitative research methods. A pilot interview was conducted with a nurse who met the study's inclusion criteria. The participant who took part in the pilot study was not included in the main study's sample. Following expert evaluation and

Table 1
Participants' demographic characteristics (n = 13).

Participants	Age	Education	Profession	Professional experience years	Health professional's KETEM experience year	Participates in cancer screenings of people with intellectual disability
P1	30	Associate degree	Health officer	12	2	No
P2	43	Bachelor's Degree	Nurse	20	3	No
P3	50	Bachelor's Degree	Nurse	29	7	No
P4	36	Secondary school	Nurse	17	4	No
P5	35	Associate degreA	Radiology technician	15	10	No
P6	45	Bachelor's Degree	Midwife	24	3	No
P7	46	Bachelor's Degree	Midwife	24	5	Yes
P8	36	Bachelor's Degree	Midwife	12	5	No
P9	46	Bachelor's Degree	Nurse	24	7	Yes
P10	48	Associate degree	Nurse	26	20	No
P11	40	Bachelor's Degree	Radiology technician	15	5	No
P12	49	Postgraduate Degree	Doctor	24	10	No
P13	30	Doctorate	Doctor	6	5	No

pilot testing, the necessary adjustments were made, no new questions were added, and the final version of the form was produced. Researchers developed 15 questions based on the literature, comprising seven main questions and eight sub-questions (Chan et al., 2022; Truong et al., 2021)(Table 2). To ensure that the interviews reached sufficient depth, the researcher asked probing questions based on the course of the interview.

A voice recorder was used to collect the data. The interview room was prepared in advance of the interview, and a sign indicating that an interview was taking place was displayed at the door. The data was collected by a female researcher (MA) who holds a doctorate in public health nursing, works in the field of cancer screening and awareness, and has conducted qualitative research. The interviews lasted between 25 and 37 minutes, varying from participant to participant.

2.4. Data Analysis

In this study, the data were analysed based on Nowell et al.'s (2017) eight-step thematic analysis approach (Nowell et al., 2017). Familiarising Oneself with the Data: The interview recordings were listened to multiple times, and the transcribed texts were read several times to establish a thorough understanding of the data. Transcribing the Data: All interviews were transcribed verbatim. Familiarising oneself with the data was also achieved in this section. Generating Initial Codes: The dataset was examined line by line, and meaningful data fragments were labeled with open codes. The coding process was performed manually, and data with similar content were grouped under the same code. Collating Codes into Categories: The obtained codes were classified according to content similarities, and categories with higher-level conceptual integrity were created. These categories were evaluated as precursors to themes. Generating Themes: Categories have been transformed into themes in more inclusive and meaningful structures. At this stage, care has been taken to ensure that each theme represents a unique dimension of participant experiences. Reviewing Themes: The identified themes were evaluated in terms of their consistency and distinctiveness by comparing them with the entire data set. Defining and Naming Themes: The final themes were described in a clear and conceptually meaningful manner, and each was assigned a name that accurately reflected the theme. Producing the Report: Themes and participant citations supporting sub-themes are presented in a holistic structure. Data analysis was performed by female researchers (RA, MA) with PhDs in nursing, many publications on cancer, and qualitative research. In addition, the final author, a female professor working on cancers in the department of public health (IAA), conducted a final review of the findings.

2.5. Trustworthiness and Transferrability

To ensure that the research was conducted in an ethical, reliable, and valid manner, attention was paid to meeting the criteria of reliability, auditability, credibility, and transferability (Strauss & Corbin, 1998). For reliability, a semi-structured interview form was prepared, and the opinions of three academics specialising in the field were sought during the analysis of the data. The interviews were transcribed verbatim, and the participants' statements were presented without any changes. For auditability, the researchers conducting the analysis continuously performed comparative analysis and reached a consensus. For credibility, the interviews were conducted actively and continuously, and sufficient time was allocated for the interviews. Additionally, the themes and sub-themes were presented to an independent qualitative research expert for their opinion, and necessary adjustments were made in line with the expert's evaluations. To enhance transferability, the principle of maximum diversity was observed in sample selection, ensuring the inclusion of participants with different characteristics.

2.6. Ethical Approval

Ethical approval for the research was obtained from the XX University Social and Human Sciences Research Ethics Committee

Table 2
The main questions.

1	What does caring for a person with intellectual disabilities mean to you?
	• What are your positive experiences in caring for a person with intellectual disabilities?
	• What are your negative experiences in caring for a person with intellectual disabilities?
2	How do you feel about coping with situations that may arise while caring for a person with intellectual disabilities?
3	How has your role as a caregiver affected your life?
4	What are the difficulties/barriers that individuals with intellectual disabilities encounter in cancer screening?
	• What challenges do individuals with intellectual disabilities face in accessing cancer screenings?
	• What challenges do individuals with intellectual disabilities face during cancer screenings?
5	How do you cope with the difficulties you experience in getting individuals with intellectual disabilities to participate in cancer screening?
6	How do you assess the attitude of the healthcare professional conducting the cancer screening towards the person with intellectual disabilities during the procedure?
7	What should be done to encourage people with intellectual disabilities to participate in cancer screening?
	• Characteristics of the area being screened…
	• Characteristics of the healthcare professional conducting the screening…
	• Characteristics of the caregiver…
	• Policies…

(Approval No: 2023–1116, Date: 29 December 2023). Institutional permission was obtained from the XXX Provincial Health Directorate. Individuals participating in the study were informed about the purpose, process, confidentiality principles, and voluntariness principles of the research; interviews were conducted after obtaining their written or verbal consent. Participants were informed that they had the right to refuse any question they wished to answer or to end the interview at any time. However, no such situation

Table 3
Theme, sub-theme and Examples of Quotations Obtained from Interviews.

Theme	Sub-theme	Examples of quotations
The Meaning of Caring for a Person with Intellectual Disabilities	**Rights**	*I believe that screening people with intellectual disabilities for cancer is much more important than screening healthy individuals. Because they cannot speak, they cannot express themselves. Their inability to express themselves may prevent them from expressing cancer symptoms, and it may be too late for early diagnosis. So, in the end, no matter how intellectually disabled they are, early diagnosis is their right (P4).*
	Professional Satisfaction And Emotional Fulfilment	*"Yes, they don't understand most things, but seeing their happiness when they see our sensitivity while caring for them, when we make eye contact, spending time with them, and informing them makes me happy. This situation can happen to any of us; we are all potential disabled people… Looking at it from an emotional point of view, I like it when I see them leaving happy, it makes me happy." (P5).*
	Emotional Burden/Stress	*"Intellectual disabilities individuals are not conscious of what is happening, meaning they are not aware of what is going on; someone brought them there, and they don't know what is happening… Regardless of the outcome, they remain unaware of anything. It saddens me to care for them…" (P10).*
	Stereotypes about Sexuality	-
Difficulties Experienced	**Communication Difficulties**	*"We have communication problems… Did they understand what I said or not… For example, if I'm going to undergo a smear test or a mammogram, will the healthcare provider follow my instructions during the procedure? Or, if the result is negative, but we can't be sure whether the person has symptoms or not. False negatives. As I said, communication problems." (P1).*
	Psychological And Physical Resistance	*"They are afraid of the equipment during screening, so positioning them and getting them into position is difficult. Perceiving the equipment, not being afraid of it… Even healthy individuals are sometimes afraid of the equipment, so what can be done?" (P6).*
	Professional Anxiety Related To A Lack Of Training	*"I feel very inadequate and inexperienced… I'm unsure how to approach them… Even as a doctor, I sometimes go with fear and anxiety… Of course, there is also a feeling of inadequacy… As healthcare workers, we often lack training on how to approach individuals with such needs. We also lack experience. Training should be provided to us on this subject."(P13).*
Coping With Difficulties	**Family And Caregiver Support**	*"As I said, since individuals with* intellectual disabilities *do not come to the screening alone, we conduct the screening in coordination with their families. We perform screenings by collaborating with the family, receiving their support, explaining as much as possible to the disabled individual, and working with the family in situations where the individual may not understand." (P2).*
	Trust-Based Approach And Person-Centred Care	*"When some individuals with intellectual disabilities leave their comfort zone, they can become aggressive around unfamiliar people, making screening impossible in such situations. In these cases, we spend time with them, communicate calmly and comfortably, and proceed with screening once we feel they trust us…" (P5).*
Encouraging Participation in Cancer Screening	**Family Doctors' Role As Coordinators İn Access And Transportation**	*"Family doctors know their neighbourhood and are aware of the disabilities of those living there. The family doctor can meet with the family and the individual one-on-one. They can refer them to the screening centre and then contact them again to facilitate their transportation…"(P8).* *"The family doctor is very important in this regard. They must identify individuals with intellectual disabilities and ensure that these individuals have access to and communication with cancer screening centres. If they inform us, our centre provides all the support necessary. I urge family doctors to be sensitive to this issue…" (P9).*
	Increasing Access To Services Through Education And Awareness	*"As KETEM, we go to municipalities, public education centres, and Quran courses to provide training on cancer screening to increase participation in cancer screening. Perhaps we can mention individuals with intellectual disabilities in these training sessions… We must explain to caregivers the importance of cancer screening in individuals with intellectual disabilities. Even most healthy people avoid screening. Individuals with intellectual disabilities are more vulnerable to neglect and abuse, so the importance of screening, especially for cervical cancer, should be explained to families and caregivers, and awareness should be raised through training…" (P2).*
	Encouraging Screening Participation Through Service Planning And Communication	*"The Ministry should set aside a specific screening time slot for individuals with intellectual disabilities at KETEM centres; monthly would be best…" (P1)* *"The Ministry of Health should make public service announcements on radio and television encouraging people with intellectual disabilities to undergo cancer screening."(P10)*

occurred.Verbal consents are included in the audio recordings. To ensure data confidentiality, all interview recordings and written transcripts obtained were stored in password-protected digital environments accessible only to the researcher. The data was not shared with any person or institution outside the research and was securely archived to be destroyed after the process was completed. The information shared by the participants was reported in a manner that did not reveal their identities or the institutions for which they worked. To maintain anonymity, participants were assigned codes instead of their real names.

3. Results

The experiences of healthcare professionals conducting cancer screening for individuals with intellectual disabilities were examined under four main themes and eleven sub-themes: the meaning of caring for an individual with intellectual disabilities, the difficulties encountered, coping with problems, and encouraging participation in cancer screening (Table 3).

3.1. Theme 1. The Meaning of Caring for an Individual with an Intellectual Disability

The meaning participants attributed to caring for individuals with intellectual disabilities was examined under four subthemes: rights, professional satisfaction and emotional fulfillment, emotional burden/stress, and stereotypes about sexuality.

3.1.1. Sub-theme 1.1. Rights

The vast majority of participants emphasized the importance of caring for individuals with intellectual disabilities during cancer screening, stressing that individuals with intellectual disabilities are human beings and have the right to participate in cancer screening. Some participants stated:

> *"After all, they are individuals too. It is their right to participate in cancer screenings. You know that in our country, people with disabilities have the right to high-level healthcare. Because they already start life at a disadvantage compared to us in terms of health…" (P1)*

3.1.2. Sub-theme 1.2. Professional Satisfaction And Emotional Fulfilment

The vast majority of participants stated that they were pleased with the participation of individuals with intellectual disabilities in cancer screenings and that seeing individuals with intellectual disabilities leave the center happy after screening provided professional satisfaction. Some of the participants' statements are as follows:

> *"Frankly, it makes me happy that their families bring their intellectual disabilities family member for cancer screening and are aware of this… Also, reaching out to them or serving them provides professional satisfaction and makes us happy." (P2)*

> *"…I am happy that they come to the cancer screening centre and that I can contribute something to them (people with intellectual disabilities)…" (P6).*

3.1.3. Sub-theme 1.3. Emotional Burden/Stress

Some participants expressed sadness that *intellectual disabilities* individuals were unaware of the procedures performed on them or the results after screening. One of the participants stated the following:

> *"First of all, it really touches my conscience. Perhaps it was because I recently became a mother and experienced pregnancy, but I was very affected the other day. Because even if they have cancer symptoms, they cannot express them. Imagine what they are going through, who knows what happens during diagnosis or treatment…" (P13).*

3.1.4. Sub-theme 1.4. Stereotypes about Sexuality

One of the participants stated that performing smear tests on people with intellectual disabilities upset them and reminded them of rape, saying:

> *When I hear that a intellectual disabilities person is going to have a Pap smear, I wonder if there has been any sexual abuse involving rape. I think to myself, as if they couldn't be married or have consensual sex. Immediately, my mind is preoccupied with the thought, "Did she get raped?" Of course, you can't question this, but I experience emotional distress because of this thought. Questions like why are they having a Pap smear, why aren't they virgins come to mind, and I feel sad." (P7).*

3.2. Main Theme 2. Difficulties Experienced

Difficulties experienced in caring for individuals with intellectual disabilities were addressed under three sub-themes: communication difficulties, psychological and physical resistance and professional anxiety related to a lack of training.

3.2.1. Sub-Theme 2.1. Communication Difficulties

Participants reported difficulties related to communication problems experienced by individuals with intellectual disabilities, such

as not understanding what was said during screenings and being unable to follow instructions during the procedure.

> *"It is difficult to get them onto the examination table or into the mammography machine; it is tough to persuade people with intellectual disabilities. They do not follow our instructions, and this leads to communication problems. Two carers are needed…" (P9).*

3.2.2. Sub-Theme 2.2. Psychological And Physical Resistance

Participants noted that during cancer screenings, intellectual disabilities individuals experienced difficulties in positioning and undergoing the procedure due to their unfamiliarity with the environment, equipment, and caregivers. Some participants stated:

> *"Positioning is difficult… Because they are out of their comfort zone, the unfamiliar environment and unfamiliar people make it difficult for them to feel secure and follow instructions for positioning…" (P11).*

> *"The environment is unfamiliar, we are strangers, and some of our disabled friends become quite aggressive. Therefore, during the procedure, especially during the smear test, they close themselves off, do not allow it, do not want to position themselves, and want to harm themselves. However, we are always by their side until we build their trust…" (P13).*

3.2.3. Sub-Theme. 2.3. Professional Anxiety Related To A Lack Of Training

Two of the participants emphasized that they had difficulty coping with the challenges they faced while caring for people with intellectual disabilities and stressed the need for training for healthcare professionals in this area. One participant stated:

> *"I don't feel confident about caring for a person with an intellectual disability. I always go with hesitation and feel uncomfortable. Frankly, we, as healthcare professionals, should be trained on how to prevent problems during care or how to address them when they arise. I definitely feel inadequate…" (P4).*

3.3. Theme 3. Coping with Difficulties

Health professionals' coping with difficulties encountered during the cancer screening process for individuals with intellectual disabilities was examined under two sub-themes: family and caregiver support, trust-based approach and person-centered care.

3.3.1. Sub-Theme 3.1. Family And Caregiver Support

The vast majority of healthcare professionals stated that when difficulties arose during screening, they resolved them with the family or caregiver of the person with intellectual disabilities. They also noted that people with intellectual disabilities usually came with two relatives or caregivers. Some participants stated:

> *"We manage somehow with the support of family or carers…" (P1)*

> *"It is tough to persuade them to participate in the screening without at least two carers. Therefore, they usually come to the screening with two people. We resolve the issue this way…" (P9).*

3.3.2. Sub-Theme 3.2. Trust-Based Approach And Person-Centered Care

Some participants stated that they were able to cope with difficulties by patiently communicating with individuals with intellectual disabilities, devoting more time to their care, and conducting screenings once they felt secure. Some participants stated:

> *"We show special attention to people with intellectual disabilities. This way, a bond of trust is formed between us, and then we conduct the screening… This makes them happy…" (P6).*

3.4. Theme 4. Encouraging Participation in Cancer Screening

Encouraging the participation of individuals with intellectual disabilities in cancer screening was examined under three sub-themes: the coordinating role of family physicians in access and transportation, increasing access to services through education and awareness, and encouraging screening participation through service planning and communication.

3.4.1. Sub-Theme 4.1. Family Doctors' Role As Coordinators İn Access And Transportation

The vast majority of participants emphasized the need for family doctors of individuals with intellectual disabilities to contact cancer screening centers to plan access and transportation to encourage these individuals to undergo cancer screening. Some participants stated:

> *"Rather than expecting the families of individuals with intellectual disabilities to bring them individually, their participation in screening should be facilitated collectively by the family doctor's planning, the municipality, or the relevant institution." (P1).*

> *"Family doctors have a great responsibility in terms of access and transportation. They are aware of the number of individuals with intellectual disabilities registered with them. They should plan access and transportation for the screening of these individuals in cooperation with us and the family." (P10).*

3.4.2. Sub-theme 4.2. Increasing Access To Services Through Education And Awareness

Some participants emphasized the need to raise awareness among families to encourage individuals with intellectual disabilities to participate in cancer screenings. They stated that training sessions should be organized for this purpose. Some participants stated:

> *"There are associations that these individuals and their families belong to. These associations should organise training specifically for caregivers and explain the importance of cancer screening at regular intervals to raise awareness…" (P12)*

> *"I believe that caregivers of individuals with intellectual disabilities have very low awareness regarding cancer screening, and this leads to a lack of demand for related services, which is problematic. Providing education to these families and raising their awareness is crucial, as individuals with intellectual disabilities are already a high-risk group for cancer…" (P13).*

3.4.3. Sub-theme 4.3. Encouraging Screening Participation Through Service Planning And Communication

Some participants suggested that the Ministry of Health should designate a specific day or time each month at screening centers to encourage individuals with intellectual disabilities to participate in cancer screenings. In contrast, others stated that social media should be used for promotion.

Some participants who stated that cancer screening centers should have a specific day and time for individuals with intellectual disabilities said the following:

> *"For cancer screening, a day should be designated in each district, at KETEM units, and that day should be reserved for individuals with intellectual disabilities. …by doing so, they can be encouraged to come here on that day…" (P4)*

Participants stated that the Ministry of Health should use social media, television, radio, and government institutions to encourage individuals with intellectual disabilities to participate in cancer screenings. Their statements are as follows:

> *"…to increase the participation of all disabled individuals, including those with intellectual disabilities, in cancer screening, the Ministry of Health should make announcements on television and social media. It should put up posters in government institutions…" (P2)*

4. Discussion

Participants in the study stated that individuals with intellectual disabilities are disadvantaged in terms of early cancer diagnosis and screening, but that screening is their right. The European Commission's "Disability Rights Strategy 2021-2030," adopted in 2021, aims to ensure that all individuals with disabilities in Europe enjoy equal human rights and opportunities (EuropeanCommission, 2021b). However, it is also noted that individuals with intellectual disabilities are generally underrepresented in cancer prevention and screening policies, leading to health inequalities and adverse health outcomes. Research conducted by Wagner and colleagues (2025) suggests that health systems and public health campaigns should strive to eliminate discrimination and enhance accessibility, emphasizing the importance of providing equal health services to all. Individuals with intellectual disabilities are at a disadvantage in accessing cancer screenings, and their underrepresentation in health policies exacerbates inequalities. The participants' emphasis on the phrase "early diagnosis is their right too" points to the need to develop inclusive strategies that will ensure equal access to healthcare services for individuals with disabilities. However, it is seen that while conducting cancer screening for individuals with intellectual disabilities, participants experience both professional satisfaction and emotional fulfillment as well as emotional burden/stress. This situation is explained in the literature through the concepts of "compassion satisfaction" and "compassion fatigue," emphasizing that caregiving can be both a source of satisfaction and exhaustion, and that emotional exhaustion decreases as satisfaction with helping others increases (Zhang et al., 2018). Communication difficulties and psychosocial barriers during the screening process for individuals with intellectual disabilities can be challenging for staff, but contributing to early diagnosis is an essential source of motivation. Indeed, a study conducted among nurses in the United States reported that nurses' increased professional contact with adults with intellectual disabilities was associated with more positive attitudes and feelings toward caring for adults with intellectual disabilities, as well as fewer negative feelings (Desroches et al., 2019). In addition, this study found that performing pap smear tests on individuals with intellectual disabilities reminded participants of the risk of sexual abuse, and this situation was addressed under the sub-theme of stereotypes about sexuality. The literature indicates that some healthcare professionals hold biased views, particularly regarding women with intellectual or developmental disabilities, assuming they are not sexually active and therefore do not require cervical cancer screening. It has been revealed that disregarding the need for Pap smear tests for individuals with intellectual disabilities could constitute a significant barrier to encouraging their participation in screening programmes(Fang et al., 2016; Plourde et al., 2018). Additionally, it is noted that the rate of sexual abuse is high among individuals with intellectual disabilities(Svae et al., 2022; Tomsa et al., 2021) and that this may increase the risk of exposure to HPV(Power et al., 2024). When participants see individuals with intellectual disabilities, they immediately think about the 'possibility of sexual assault.' This demonstrates both an awareness of this risk and the persistence of stereotypes that these individuals cannot have a consensual sex life. Rather than encouraging the participation of individuals with intellectual disabilities in screening programmes at a low rate, it is clear that their access to these services should be supported through a rights-based approach. However, media coverage or social processes involving sexual abuse of individuals with intellectual disabilities may have negatively influenced the participant's views, as society perpetuates gender-based myths about the sexual nature of individuals with intellectual disabilities and their presence in society, indirectly affecting individuals. All these reasons can be expressed as factors that reveal the participant's sex-based prejudiced view of the pap smear test.

In this study, healthcare professionals also reported encountering communication difficulties and psychological and physical resistance from individuals during the screening process. Similarly, the literature emphasizes that individuals with intellectual disabilities are medically vulnerable, develop anxiety towards unfamiliar environments, and experience difficulties in early diagnosis due to communication problems (Chan et al., 2022; Emerson et al., 2016; Wagner et al., 2025). Insufficient information sharing during diagnosis and treatment processes can be seen to create barriers to intellectual disabled individuals accessing healthcare services. It is stated that relatives and healthcare professionals, assuming that individuals with intellectual disabilities will not understand, provide them with limited information, which leads to a violation of the individual's rights to autonomy and information. Therefore, it is stated that the resistance seen in cancer screening is not only procedural but also stems from limitations in access to information and autonomy. (Glasdam et al., 2025). However, it is anticipated that providing practical communication training for healthcare professionals and developing person-centered care approaches will both increase the effectiveness of the screening process and support the active participation of individuals with intellectual disabilities in the process (Shady et al., 2024; Vukovic et al., 2023; Wagner et al., 2025). The findings of this study indicate that effective communication training for healthcare professionals and the organization of screening environments in an accessible and supportive manner are necessary to increase the success of cancer screenings, and these findings are consistent with the existing literature.

A study conducted in the United States found that only 40.7% of doctors reported confidence in their ability to provide quality care to individuals with disabilities (Geukes et al., 2019). A study examining the experiences of individuals with intellectual disabilities during the colorectal cancer screening process indicated that there is a concerning lack of trained healthcare professionals to provide adequate care to individuals with intellectual disabilities. The same study stated that individuals with intellectual disabilities had distressing experiences due to reasons such as the negative attitudes and behaviors of healthcare providers, lack of knowledge about intellectual disability, and lack of expertise (Wagner et al., 2025). Findings from another study emphasized the need for experience-based training to improve healthcare professionals' attitudes toward individuals with intellectual disabilities (Alnahdi, 2025). It has been stated that healthcare settings can become more inclusive and supportive through improved training programs, and better healthcare outcomes can be achieved for individuals with intellectual disabilities (Alnahdi, 2025). Healthcare systems globally need to contribute to communication, training, and support for clinicians working with individuals with intellectual disabilities, particularly in the area of cancer prevention. The failure to address educational deficiencies related to intellectual disability can lead to adverse health outcomes for this group (Howie et al., 2021). As emphasized in the literature, increasing disability-specific education and experience-based practices enables professionals to improve the quality of care and provide more inclusive services.

In this study, healthcare professionals who screen individuals with intellectual disabilities reported that family support and a trust-based, person-centered approach are crucial in coping with the challenges encountered during the screening process, and that they employed these strategies to address these difficulties. Person-centered care comprises eight core components: respecting the individual's values and preferences, providing information and educational support, ensuring access to and continuity of care, offering emotional support, involving family and friends in the process, ensuring physical comfort, and effectively coordinating care (Berghout et al., 2015). The literature emphasizes that family and caregiver support is vital for individuals with intellectual disabilities to access health services, including screening (Armin et al., 2022; Klara et al., 2024). It has been noted that caregivers take on responsibilities such as acting as intermediaries in communication between the individual and healthcare professionals (Armin et al., 2022). Therefore, it is expected that the development of structured support programs encompassing all components of person-centered care in healthcare services will both facilitate professionals' ability to cope with difficulties and improve the healthcare experiences and participation of individuals with intellectual disabilities.

Family physicians play a crucial role in cancer prevention and early diagnosis activities due to their position in the healthcare system, their frequent contact with patients, and their impact on the local community in which they operate. It has been determined that integrating cancer prevention and early diagnosis activities into the daily work of family physicians plays a crucial role in achieving excellent results (Marijanović et al., 2021). In the United Kingdom, family physicians play a leading role in the effective delivery of screening and health promotion programs to individuals with intellectual disabilities(McMahon et al., 2024). However, individuals with intellectual disabilities often require support to access healthcare services, yet their families and caregivers lack sufficient knowledge about cancer prevention and screening. Due to low health literacy, these individuals struggle to recognize cancer symptoms and are often unable to express their complaints (Cuypers et al., 2020). A study conducted with individuals with intellectual disabilities indicated that awareness-raising campaigns are important for eliminating discrimination and increasing accessibility in screening programs. It was recommended to use accessible formats, such as simple language and visual aids, to ensure that everyone is aware of the screenings. Research findings revealed that accessible, barrier-free invitation letters (e.g., simple language, visual aids, clear explanations of the steps to be taken) and educational booklets serve as important facilitators (Wagner et al., 2025). However, it has been emphasized that implementing reasonable accommodations, such as increasing the length of appointments and making information accessible, is extremely important across all healthcare services to meet the needs of individuals with intellectual disabilities (McMahon et al., 2024). The study reveals that family physicians' coordinating role, accessible communication, and reasonable accommodations are essential in healthcare services to ensure equal participation of individuals with intellectual disabilities in cancer screenings.

4.1. Strengths and Limitations

This study has particular strengths and limitations. One of the strengths of this study is that it addresses cancer screening services for individuals with intellectual disabilities through the experiences of healthcare professionals from different occupational groups. Thus, by focusing on the professional perspective, which is often neglected in the literature, the study aims to fill an essential gap in the

field. The qualitative research design used in the study enabled an in-depth examination of healthcare professionals' opinions, attitudes, perceptions, and decision-making processes. Furthermore, by revealing the implicit assumptions and stereotypes of healthcare professionals, the study contributes to understanding the individual, structural, and cultural factors that influence cancer screening services.

The limitations of the study are that, due to the qualitative research design, the findings are not generalizable and reflect only the experiences of the healthcare professionals who participated in the study and may differ across institutional or cultural contexts. Furthermore, the study's focus solely on the perspectives of healthcare professionals does not directly include the experiences of individuals with intellectual disabilities and caregivers; this should be considered a conscious methodological choice appropriate to the study's purpose, as it limits the inclusion of multiple perspectives on screening processes within the same survey.

5. Conclusion

It has been determined that healthcare professionals experience professional satisfaction while providing care to individuals with intellectual disabilities, but at the same time, they face challenges during this process. It has been observed that healthcare professionals try to cope with the difficulties encountered in communication and interaction during the screening process with the support of families and caregivers. In order to conduct the screening process more effectively with individuals with intellectual disabilities and to increase their participation in cancer screening, it has been determined that awareness training should be provided to healthcare professionals, families, and the community, It has been determined that healthcare professionals and managers working in screening units need to collaborate to restructure services aimed at increasing the participation of individuals with intellectual disabilities in cancer screening programs.

Ethics statement

Ethical approval for the research was obtained from the Ondokuz Mayıs University Social and Human Sciences Research Ethics Committee (Approval No: 2023–1116, Date: 29 December 2023).

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

References

Alnahdi, G. (2025). Healthcare providers' attitudes toward individuals with intellectual disabilities: Implications for education and practice in Saudi Arabia. *Research in Developmental Disabilities, 162*, Article 105026. https://doi.org/10.1016/j.ridd.2025.105026

American Psychiatric Assosiation. (2024). *What is Intellectual Disability?* American Psychiatric Assosiation. ⟨https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability⟩.

Armin, J. S., Williamson, H. J., Begay, A., Etcitty, J., Attakai, A., Russell, K., & Baldwin, J. A. (2022). Adapting a Cancer Screening Education Program for Native American Women with Disabilities. *Int J Environ Res Public Health, 19*(15). https://doi.org/10.3390/ijerph19159280

Banda, A., Naaldenberg, J., Timen, A., van Eeghen, A., Leusink, G., & Cuypers, M. (2024). Cancer risks related to intellectual disabilities: A systematic review. *Cancer Med, 13*(9), Article e7210. https://doi.org/10.1002/cam4.7210

Berghout, M., Van Exel, J., Leensvaart, L., & Cramm, J. M. (2015). Healthcare professionals' views on patient-centered care in hospitals. *BMC Health Services Research, 15*(1), 385.

Breau, G., Thorne, S., Baumbusch, J., Hislop, T. G., & Kazanjian, A. (2020). Primary Care Providers' Attitudes Towards Recommending Cancer Screening to Patients With Intellectual Disability: A Cross-Sectional Survey. *Inclusion, 8*(3), 185–193.

Breau, G., Thorne, S., Baumbusch, J., Hislop, T. G., & Kazanjian, A. (2023). Family physicians' and trainees' experiences regarding cancer screening with patients with intellectual disability: An interpretive description study. *J Intellect Disabil, 27*(1), 250–265. https://doi.org/10.1177/17446295211044041

Caton, S., Chadwick, D., Chapman, M., Turnbull, S., Mitchell, D., & Stansfield, J. (2012). Healthy lifestyles for adults with intellectual disability: knowledge, barriers, and facilitators. *J Intellect Dev Disabil, 37*(3), 248–259. https://doi.org/10.3109/13668250.2012.703645

Chan, D. N., Law, B. M., Au, D. W., So, W. K., & Fan, N. (2022). A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities. *Cancer Epidemiology, 76*, Article 102084.

Creswell, J. W., & Poth, C. N. (2016). Sage publications. *Qualitative Inquiry and Research design: Choosing among five Approaches*.

Cuypers, M., Schalk, B. W. M., Boonman, A. J. N., Naaldenberg, J., & Leusink, G. L. (2022). Cancer-related mortality among people with intellectual disabilities: A nationwide population-based cohort study. *Cancer, 128*(6), 1267–1274. https://doi.org/10.1002/cncr.34030

Cuypers, M., Tobi, H., Huijsmans, C. A., van Gerwen, L., Ten Hove, M., van Weel, C., Kiemeney, L. A., Naaldenberg, J., & Leusink, G. L. (2020). Disparities in cancer-related healthcare among people with intellectual disabilities: a population-based cohort study with health insurance claims data. *Cancer Medicine, 9*(18), 6888–6895.

Desroches, M. L., Sethares, K. A., Curtin, C., & Chung, J. (2019). Nurses' attitudes and emotions toward caring for adults with intellectual disabilities: Results of a cross-sectional, correlational-predictive research study. *Journal of Applied Research in Intellectual Disabilities, 32*(6), 1501–1513.

DSM. (2013). *DSM-Diagnostic and statistical manual of mental disorders: DSM-5* [doi:10.1176/appi.books.9780890425596]. American Psychiatric Publishing, Inc. https://doi.org/10.1176/appi.books.9780890425596.

Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: cross sectional study. *International Journal for Equity in Health, 15*(1), 11.

EuropeanCommission. (2021a). Europe's Beating Cancer Plan Communication from the commission to the European Parliament and the Council. In. ⟨https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf⟩.

EuropeanCommission. (2021b). *Union of Equality: Strategy for the Rights of Persons with Disabilities for 2021–2030.*. ⟨https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes⟩.

Fang, W.-H., Yen, C.-F., Hu, J., Lin, J.-D., & Loh, C.-H. (2016). The utilization and barriers of Pap smear among women with visual impairment. *International Journal for Equity in Health, 15*(1), 65.

Geukes, C., Bröder, J., & Latteck, Ä.-D. (2019). Health literacy and people with intellectual disabilities: What we know, what we do not know, and what we need: A theoretical discourse. *International Journal of Environmental Research and Public Health, 16*(3), 463.

Glasdam, S., Cohen, M., Soffer, M., & Fu, C. (2025). Experiences and strategies of individuals with concomitant intellectual disabilities and cancer: a qualitative systematic literature review. *Frontiers in Cancer Control and Society, 3*, Article 1659795.

Golubović, Š., Simin, D., Vuković, V., Demirović, S., & Milutinović, D. (2024). Exploring Cancer Prevention Challenges for People with Intellectual Disabilities: Perspectives from Family Caregiver. *Healthcare*.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59–82.

Hansford, R., Ouellette-Kuntz, H., Bourque, M. A., Decker, K., Derksen, S., Hallet, J., Dawe, D. E., Cobigo, V., Shooshtari, S., Stirling, M., Kelly, C., Brownell, M., Turner, D., & Mahar, A. L. (2024). Investigating inequalities in cancer staging and survival for adults with intellectual or developmental disabilities and cancer: A population-based study in Manitoba, Canada. *Cancer Epidemiol, 88*, Article 102500. https://doi.org/10.1016/j.canep.2023.102500

Heslop, P., Cook, A., Sullivan, B., Calkin, R., Pollard, J., & Byrne, V. (2022). Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. *BMJ Open, 12*(3), Article e056974. https://doi.org/10.1136/bmjopen-2021-056974

Howie, V. A., Welch, A. J., Horton, E. S., & Wirihana, L. A. (2021). The quandary of registered nurses untrained in adult intellectual disability nursing when caring for this diverse patient group in acute care settings: An integrated literature review. *Journal of Clinical Nursing, 30*(11-12), 1542–1555.

Hsieh, K., Rimmer, J. H., & Heller, T. (2014). Obesity and associated factors in adults with intellectual disability. *J Intellect Disabil Res, 58*(9), 851–863. https://doi.org/10.1111/jir.12100

Klara, S., Elmadani, M., Éva, H., Lívia, T., Mbaabu, G., Hamad, O. F., Mesmar, A., Andrade, D., & Mate, O. (2024). Cancer Prevention in Adults with Intellectual Disabilities: A Systematic Literature Review of Caregiver Perspectives in Institutional and Home Care Settings. *International Journal of Environmental Research and Public Health, 21*(11), 1402.

Kuper, H., & Azizatunnisa', L. (2025). Cancer screening inequities and people with intellectual disabilities—what should we do to close the gaps? *The Lancet Public Health, 10*(3), e166–e167. https://doi.org/10.1016/S2468-2667(25)00037-4

LeCompte, M., & Preissle, J. (1993). *Ethnography and Qualitative Design in Educational Research*. San Diego, CA: Academic. Language.

Lee, K., Cascella, M., & Marwaha, R. (2021). *Intellectual disability.[Updated 2021 Aug 11]*. StatPearls.

Liu, Q., Adami, H. O., Reichenberg, A., Kolevzon, A., Fang, F., & Sandin, S. (2021). Cancer risk in individuals with intellectual disability in Sweden: A population-based cohort study. *PLoS Med, 18*(10), Article e1003840. https://doi.org/10.1371/journal.pmed.1003840

Mahar, A. L., Biggs, K., Hansford, R. L., Derksen, S., Griffiths, R., Enns, J. E., Dawe, D. E., Hallet, J., Kristjanson, M., Decker, K., Cobigo, V., Shooshtari, S., Stirling, M., Kelly, C., Brownell, M., Turner, D., & Ouellette-Kuntz, H. (2024). Stage IV breast, colorectal, and lung cancer at diagnosis in adults living with intellectual or developmental disabilities: A population-based cross-sectional study. *Cancer, 130*(5), 740–749. https://doi.org/10.1002/cncr.35068

Marijanović, I., Kraljević, M., Bevanda Glibo, D., Buhovac, T., & Černi Obrdalj, E. (2021). The Role of Family Physicians in the Prevention and Early Detection of Cancer in Herzegovina-Neretva and West-Herzegovina Canton. *Psychiatr Danub, 33*(10), 89–96.

Mbemi, A., Khanna, S., Njiki, S., Yedjou, C. G., & Tchounwou, P. B. (2020). Impact of Gene-Environment Interactions on Cancer Development. *Int J Environ Res Public Health, 17*(21). https://doi.org/10.3390/ijerph17218089

McIlfatrick, S., Taggart, L., & Truesdale-Kennedy, M. (2011). Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. *European Journal of Cancer care, 20*(3), 412–420.

McMahon, M., McCallion, P., & McCarron, M. (2024). An invisible population: Late-stage cancer diagnosis for people with intellectual or developmental disability. *Cancer (0008543X)*, (5), *130*.

Nguyen, A. D. K., Meehan, K., Redfern, A. D., Brown, A., Robinson, M., Papertalk, L., & Thompson, S. C. (2025). The impact of genetics and the environment on cancer risk in Indigenous Australians: a narrative review. *The Lancet Regional Health - Western Pacific, 61*, Article 101627. https://doi.org/10.1016/j.lanwpc.2025.101627

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of qualitative Methods, 16*(1), Article 1609406917733847.

Plourde, N., Brown, H. K., Vigod, S., & Cobigo, V. (2018). The association between continuity of primary care and preventive cancer screening in women with intellectual disability. *American Journal on Intellectual and developmental disabilities, 123*(6), 499–513.

Power, R., David, M., Strnadová, I., Touyz, L., Basckin, C., Loblinzk, J., Jolly, H., Kennedy, E., Ussher, J., Sweeney, S., Chang, E.-L., Carter, A., & Bateson, D. (2024). Cervical screening participation and access facilitators and barriers for people with intellectual disability: a systematic review and meta-analysis [Review]. *Frontiers in Psychiatry, 15 - 2024*. https://doi.org/10.3389/fpsyt.2024.1379497

Raza, S. A. (2025). Emerging Trends in Global Cancer Epidemiology. *Cancers (Basel), 17*(9). https://doi.org/10.3390/cancers17091483

Reif, S., Karriker-Jaffe, K. J., Valentine, A., Patterson, D., Mericle, A. A., Adams, R. S., & Greenfield, T. K. (2022). Substance use and misuse patterns and disability status in the 2020 US National Alcohol Survey: A contributing role for chronic pain. *Disabil Health J, 15*(2s), Article 101290. https://doi.org/10.1016/j.dhjo.2022.101290

Sappok, T., Rosenbusch, M. L., Hering, R., Schulz, M., Kowalski, C., Sibert, N. T., Seufferlein, T., & Berger, A. W. (2025). Cancer prevalence and care disparities among individuals with intellectual disabilities: a cross-sectional pan-cancer analysis. *ESMO Real World Data and Digital Oncology, 9*, Article 100160. https://doi.org/10.1016/j.esmorw.2025.100160

Shady, K., Phillips, S., & Newman, S. (2024). Barriers and Facilitators to Healthcare Access in Adults with Intellectual and Developmental Disorders and Communication Difficulties: an Integrative Review. *Review Journal of Autism and Developmental Disorders, 11*(1), 39–51. https://doi.org/10.1007/s40489-022-00324-8

Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed.)*. Sage Publications.

Svae, G. B., Blixt, L., & Søndenaa, E. (2022). Personal and sexual boundaries: the experiences of people with intellectual disabilities. *BMC Public Health, 22*(1), 1773. https://doi.org/10.1186/s12889-022-14181-x

Tomsa, R., Gutu, S., Cojocaru, D., Gutierrez-Bermejo, B., Flores, N., & Jenaro, C. (2021). Prevalence of sexual abuse in adults with intellectual disability: Systematic review and meta-analysis. *International Journal of Environmental Research and Public Health, 18*(4), 1980.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health care, 19*(6), 349–357.

Truong, A., Alverbratt, C., Ekström-Bergström, A., & Antonsson, H. (2021). Caring for Persons With Intellectual Disabilities and Challenging Behavior: Staff Experiences With a Web-Based Training Program. *Front Psychiatry, 12*, Article 580923. https://doi.org/10.3389/fpsyt.2021.580923

Vukovic, V., Banda, A., Carneiro, L., Dogan, S., Knapp, P., McMahon, M., Milutinovic, D., Soylar, P., Sykes, K., & Tosun, B. (2023). The importance of cancer prevention policies to inform and guide preventative and screening measures for people with intellectual disabilities: The COST project "Cancer-Understanding Prevention in Intellectual Disabilities". *Journal of Intellectual Disabilities*, Article 17446295231213752.

Wagner, T., Herscovici, A. R., Fuchs, A., Kabas, S., Hilbert, M., König, L. M., Unseld, M., & Zeilinger, E. L. (2025). Towards Inclusive Colorectal Cancer Screening: Experiences and Needs of Adults With Intellectual Disabilities. *Cancer Med, 14*(17), Article e71212. https://doi.org/10.1002/cam4.71212

WHO. (2025). *Cancer*. ⟨https://www.who.int/news-room/fact-sheets/detail/cancer⟩.

Zhang, Y.-y, Zhang, C., Han, X.-R., Li, W., & Wang, Y.-l (2018). Determinants of compassion satisfaction, compassion fatigue and burn out in nursing: A correlative meta-analysis. *Medicine, 97*(26). ⟨https://journals.lww.com/md-journal/fulltext/2018/06290/determinants_of_compassion_satisfaction,.10.aspx⟩.