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Experiences and strategies of individuals with concomitant intellectual disabilities and cancer: a qualitative systematic literature review

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Background: Cancer care for individuals with intellectual disabilities (ID) is challenging, with evidence of disparities, late diagnoses, and overlooked experiences of the individuals in question.

Aim: To explore how individuals with concomitant ID and cancer experience the illness and navigate cancer care trajectories and everyday life from perspectives of themselves, their relatives and professionals.

Method: A qualitative systematic literature review was conducted across the databases PubMed, EMBASE, CINAHL Complete, ERIC, SocINDEX, PsycInfo, and Scopus, supplemented by a final search in Google Scholar. All studies were screened and selected in Covidence according to predefined inclusion and exclusion criteria. The review included 16 publications, registered in PROSPERO (CRD420251042718) and followed the PRISMA guidelines. The quality of the included publications was assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research. Data extraction was followed by a descriptive summary and a qualitative thematic analysis, inspired by Braun and Clarke.

Results: The studies, conducted in four countries, represented the voices of 22 individuals with ID and cancer and, in addition, perspectives of 11 relatives and 32 professionals. Data was synthesized in four themes: *"Emotional responses to having cancer," "Coping with cancer - life went on," "Balancing the right to information and the limits of communication abilities," and "Encountering death in various ways."* Individuals with ID responded to cancer and related challenges in diverse ways, yet they often demonstrated an ability to live in the moment as a coping strategy and strength in living and dying with cancer. They received information to varying degrees about their cancer diagnosis, treatment, and prognosis, while also having differing capacities to understand and process this information. Experiences of cancer in others contributed to their understanding of their own condition.

Conclusion: Individuals with ID responded to cancer and its trajectory in varied ways. Many faced challenges in interactions with healthcare professionals, often due to communication barriers. Everyday routines and "living in the moment" served as important coping strategies. All 22 voices of individuals with ID represented in the studies came from the United Kingdom. Worldwide, future research should actively involve this population throughout the process.

Systematic review registration: https://www.crd.york.ac.uk/PROSPERO/view/CRD420251042718, PROSPERO: CRD420251042718.

KEYWORDS

cancer, communication, encounters, experiences, intellectual disabilities, healthcare, qualitative systematic literature review, strategies

Introduction

A recent study found that in 2019 there were 107.62 million individuals with intellectual disabilities (ID) worldwide (1.74%). Significant regional inequalities exist in the prevalence and trends of ID across countries (1). ID is defined as a condition that occurs before the age of 22 and features major limitations in intellectual functioning and adaptive behavior (2, 3). In recent decades, life expectancy for people with ID has increased significantly in developed countries. The extension of life expectancy concomitantly elevates the risk of developing various forms of diseases, including cancer (4, 5). Therefore, the percentage of individuals with ID receiving a cancer diagnosis is progressively on the rise (5). Moreover, research shows that compared to the general population, people with ID experience more mental and physical morbidity and have higher mortality rates (6).

A recent study found that cancer survival rates were poorer among individuals with ID compared to the general population (7). However, Banda et al. (4) demonstrate that the overall cancer risk among individuals with ID is either lower than or comparable to that of the general population. Nevertheless, certain conditions, such as Down syndrome, specific genetic mutations, and premature aging presented in this population, may increase the risk of certain types of cancer (4, 8).

Cancer care is understudied among individuals with ID (9). Scant research suggests that individuals with ID encounter disparities throughout the entire range of cancer care (4). Several studies, for example, indicate that this group of individuals experiences disparities in cancer screening (8, 10, 11). Individuals with ID face multiple barriers to cancer screening, including emotional distress, communication challenges, and limited knowledge (12, 13). In addition, significant barriers exist in healthcare accessibility and provision of appropriate accommodations in medical settings (8, 13). Apart from disparities in screening, individuals with ID were often diagnosed at advanced stages of cancer (5, 14, 15). Studies provide examples of key barriers to cancer care for people with disabilities; these include a lack of evidence for making treatment decisions, ableist attitudes among healthcare professionals, erroneous assumptions among healthcare professionals about people with disabilities, such as beliefs about the values or preferences of people with disabilities, inadequate knowledge about the impairment, diagnostic overshadowing that entails assuming that symptoms are related to the person's impairment, and failure to anticipate functional implications of cancer treatment (8, 16, 17). There is very little research on cancer treatment and outcomes in people with disabilities or ID (8, 9, 13). Evidence suggests that in several cases treatment is withheld or modified based on subjective opinion of professionals (9). Boonman et al. (18) conclude that individuals with ID are medically vulnerable and may respond differently to standard cancer treatments compared to the general population.

Despite the increased awareness of disparities in cancer care for individuals with ID, investigations into the experiences of individuals with ID remain scarce, and their perspectives have not been adequately represented (19). Cancer patients with ID constitute a 'transparent population' in terms of research and clinical reports. Moreover, the limited knowledge of their experiences of diagnosis and treatment is from the viewpoint of researchers and clinicians. Their voices, especially the challenges encountered by them and their caregivers in managing cancer, are often not heard (5). This literature review aims to explore how individuals with concomitant ID and cancer experienced the illness and navigated cancer care trajectories and everyday life from perspectives of themselves, their relatives and health- and social care professionals.

Method

This study drew on a qualitative systematic literature review (20), synthesizing findings from studies on cancer and individuals with ID. A thematic analysis was conducted, inspired by Braun and Clarke (21). The review was registered in PROSPERO (registration no CRD420251042718). It followed the PRISMA guidelines (22).

Identifying the research question

Overall, we identified three research questions:

- How did individuals with ID experience their cancer diagnosis and treatment?
- What barriers and facilitators did individuals with concomitant ID and cancer encounter across the cancer care process/spectrum.
- What coping strategies did individuals with concomitant ID and cancer use to navigate and manage their treatment/care courses?

Inclusion and exclusion criteria

The inclusion criteria were: (1) Studies about diagnostic, treatment and care of individuals with ID and cancer, (2) Perspectives of individuals with ID and cancer, their relatives, and health- and social care professionals, (3) Individuals $\geq$ 18 years old, (4) Qualitative studies or qualitative sub-studies in mixed method studies, (5) Published in Chinese, English, Hebrew, or Scandinavian languages, and (6) Published between 1 January 2005 and 21 May 2025. A 20-year period has been chosen because there is relatively little research in the field. The review excluded the following types of publications: (1) Editorials and commentaries, (2) Systematic literature reviews, (3) Intervention studies, (4) Dissertations and thesis, and (5) Guidelines and recommendations.

Searching, selecting, appraising, and extracting relevant data

A comprehensive literature search was conducted in the PubMed, EMBASE, CINAHL Complete, ERIC, SocINDEX, and PsycInfo databases, with the support of an experienced

librarian (last search: 21 May 2025). The inclusion and exclusion criteria were guided by the PEO model, Population, Exposure, and Outcome (Table 1), which was chosen for its structured approach to formulating research questions and organizing data in line with qualitative research methodologies (20, 23). The search strategy was developed using the building block approach, structured according to the PEO framework.

Search terms within each PEO block were adapted to meet the specific indexing and search functionalities of each database. A detailed overview of the search strategies is presented in Table 2.

The initial search yielded 3,727 publications, which were imported into Covidence software for the screening process. Two authors (SG and CF) independently screened all records against the eligibility criteria. Discrepancies were initially discussed between them, and unresolved cases were referred to the remaining authors (MC and MS) for consensus. To uncover additional relevant studies, we conducted a citation pearl search in the Scopus database and searched on an academic online search engine, Google Scholar (last searched on 26 May 2025). The study selection process is illustrated in a PRISMA flow diagram (Figure 1).

The following information was extracted from the included publications: authorship, geographical location, journal, study period, design, sample size, target group and context, theoretical framework or concepts, key findings, and reported limitations. A selection of this data is presented in Table 3. All extracted data were reviewed for accuracy by SG, MC and CF. The CASP qualitative checklist was used to systematically assess the quality of included studies by SG and MC, ensuring the review's findings were grounded in credible evidence and methodological rigor (24). Any discrepancies were discussed in the author team until consensus was reached. Endorsed by the Cochrane Qualitative and Implementation Methods Group (25), the ten-question tool evaluated aspects such as study aims, design, recruitment, data collection and analysis, and overall significance. This appraisal ensured the evidence was robust and relevant to the research question.

Analytical strategy

The data analysis strategy comprised two components: a descriptive summary, presented as "*Characteristics of the studies*," and a reflexive thematic analysis inspired by the approach developed by Braun and Clarke (21). The analysis focused on the results sections of the included publications, which were systematically coded. These initial codes were then reorganized in relation to the review's overarching aim and research questions. Preliminary themes were generated by identifying patterns of similarity and difference across the coded data, with similar codes grouped together into broader thematic categories. Theme development was an iterative and collaborative process among three of the authors (SG, MC, CF). Themes were refined through repeated engagement with the empirical material, the initial codes, and the research question to ensure conceptual coherence and empirical grounding (2022). Each theme was subsequently defined, reviewed, and named to ensure clarity, internal consistency, and analytical rigor. The final themes were "*Emotional responses to having cancer*," "*Coping with cancer - life went on*," "*Balancing the right to information and the limits of communication abilities*," and "*Encountering death in various ways.*" They were narratively described by synthesizing the results of the included studies to address the aim of the review.

Results

Characteristics of the studies

In total, 16 publications based on seven studies were included. One study resulted in nine included publications (26–33), and another study resulted in two included publications (34, 35). The remaining five publications were based on five corresponding studies. The publications originated from the United Kingdom (13), the Netherlands (1), the United States of America (1), and Australia (1), see Table 3. The two studies that resulted in more than one included publication, used non-participant observation and semi-structured interviews. However, three of those publications only used selected cases from the entire study as empirical material (27, 28, 30). Two studies used semi-structured interviews (36, 37), two studies were case studies (38, 39) and one study constructed a case based on semi-structured interviews (40). Seven publications used narrative case description (28–30, 38, 39), four publications used grounded theory (31–33, 37), three publication used thematic analysis (34–36), one used narrative analysis (40) and one publication had an unknown analytical strategy (26).

The seven studies represented by the 16 publications included a total of 22 individuals with ID and cancer, 11 relatives, 32 health- and social care professionals, inclusive paid caregivers. The current review did not include data from the studies related to four individuals with ID (not cancer), two volunteers, and seven relatives and 16 health and social care professionals related to six deceased individuals with ID (not cancer). The current literature review only focused on the results related to individuals with ID and cancer.

Most of the studies primarily focused on individuals with ID and cancer and their experiences and care trajectories. However, Moore and Kates' (39) study focussed healthcare practices in encounters with individuals with ID and cancer, nonetheless parts of the publication revealed the patient's experiences hence it was included (39). Bekkema et al. (36) focussed on the end of life of people with ID where significant others of deceased people with ID narrated about the situations. Six out of 12 cases were about individuals with ID and cancer, and these cases were included in the current literature review (36). Nine publications were published in specific disability journals, five were published in oncological and palliative care journals (31, 32, 35, 37, 39), one in journal of general practice (31) and one in a general nursing journal (33).

All included publications demonstrated appropriate methodological rigor based on the results of the CASP checklist (24), see Table 4.

TABLE 1 Populations, exposures, and outcomes (PEO) customized to each database.

Population (P)–block 1	Exposure (E)–block 2	Outcome (O)–block 3
Patients, relatives, healthcare professionals	Intellectual disabilities and cancer	Patients' experiences and navigations of cancer care trajectories and everyday life
Patient* OR Client* OR Citizen* OR Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Workers OR Social Work* OR Formal care* OR Relative* OR Famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR Extended family* neighbors	Cancer OR Malignant disease* OR Malignancy OR Neoplasms OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasms* OR Sarcoma* AND Intellectual disabilit* OR Learning disabilit* OR mental retard* OR Down syndrome OR Development disabilit*	Experience* OR Everyday Life OR Encount* OR Involvement OR Daily living OR Participation OR Shared decision making OR Relationship* OR Interaction* OR Communication OR Information OR Activities of Daily Living OR Discrimination* OR Stigma* OR Prejudice* OR Interpersonal Relations OR Communication OR Stakeholder OR Participation OR Social Participation OR Patient Participation OR Community OR Participation OR Adaptation OR Psychological OR Information OR Dissemination OR Consumer Health OR Information OR life experience* OR activities of daily living OR participat* OR involv* OR decision making OR interpersonal relation* OR communicat* OR informat* OR coping* OR cope* OR care trajectory* OR Health care OR Healthcare

Emotional responses to having cancer

From the perspective of relatives, individuals with ID lived dependently, with others making key decisions about treatment, living arrangements, pain relief, and information about cancer diagnosis or prognosis. Their cancer experiences were shaped by others, often without full knowledge or agency (30, 31). Some individuals with ID experienced that cancer was inevitably fatal from family members or celebrities who had died of cancer (26, 27, 32). From the perspectives of relatives and professionals, some individuals with ID did not fully comprehend the seriousness of the illness, which allowed them to remain undisturbed and in good spirits (36, 37). Others recognized their situation and some deliberately chose to endure fear and restlessness rather than accept medication or hospitalization, despite professionals' and relatives' wishes for active treatment (36). From the perspective of some individuals with ID and cancer, many struggled to make sense of what was happening to their bodies, and this confusion became a central challenge of living with cancer. Some individuals with ID also expressed their confusion (29, 32). Others reacted to their cancer disease and deteriorating health with passive acceptance of their condition, marked by a lack of inquiry, and showing minimal expressions or behavioral signs of distress, anxiety or any other emotional reactions (30, 32, 37, 40). Some, particularly among those with mild ID who could express themselves, had only a limited understanding of their situation and felt powerless to ask for or seek information (33, 36, 37). Some individuals with ID denied their disease, or consciously chose to disconnect (37). Others had a high level of distress and anxiety during the cancer care trajectory (31–33, 38). From the perspective of professionals and relatives, routine medical procedures, including blood pressure monitoring and blood tests, and chemotherapy required general anesthesia for certain individuals with ID, as such interventions frequently triggered severe distress and agitation (38). Other individuals with ID experienced such intense worry that it disrupted their sleep or left them confused about why they were not being admitted to hospital (31).

Some individuals with ID and cancer had the ability to hide their distress (31) and symptoms (28) as a result of long-term socialization of individuals with ID to suppress negative emotions such as distress or anger, and the perceived requirement of carers to behave in a 'good' and compliant way (28, 33, 37, 40). From relatives' and individuals with ID's perspectives, some individuals with ID mirrored the emotional responses of relatives, who themselves attempted to hide feelings of sorrow or concern (28, 37). In addition, some individuals nearing death concealed their emotions to avoid burdening relatives and professionals (28, 31, 33, 37). Others expressed their emotions in different ways. For example, some individuals with ID who had limited spoken language communicated their immediate needs and enjoyed life through sensory experiences like water, music, and bright lights (26). Despite having cancer, they often appeared unconcerned about their prognosis. From the perspectives of professionals and relatives, cheerful attitudes might protect them from distress and worries for the future (26, 32). However, some individuals experienced severe cancer pain intensified by existential distress, even when they appeared cheerful (26, 31). Others experienced that confusions intensified as their physical abilities declined, for example, with the loss of the ability to walk or significant weight loss (28, 31, 32)

In addition, everyday activities such as travel, meals, and hygiene became emotionally challenging during their cancer care trajectories (28). Some of the individuals with ID and cancer expressed feelings of loneliness, both in physical sense of being alone and in emotional sense of lacking someone to share their fears and struggles with (27, 31, 33).

Coping with cancer - life went on

Individuals with ID expressed a strong focus on the present moment and attempted to cope with cancer by engaging in familiar daily activities such as listening to music, caring for pets, attending day centers, or enjoying small pleasures like food (27, 29, 30, 33, 39). Often, their embodied ability to live in the present moment helped protect them from the harmful effects of worry. Individuals with ID, particularly those with more severe disabilities, already possessed the skill of "living one day at a time" (26, 28, 30, 33). Relatives and professionals also expressed that individuals

TABLE 2 Search strategies (search date: 21052025).

Search	Search terms	Results
PubMed		
#1	"Intellectual Disability"[Mesh]	109,977
#2	Intellectual disabilit*[Title/Abstract] OR ID[Title/Abstract] OR Learning disabilit*[Title/Abstract] OR mental retard*[Title/Abstract] OR Down syndrome[Title/Abstract] OR developmental disabilit*[Title/Abstract] OR mental deficien*[Title/Abstract]	141,107
#3	#1 OR #2	201,895
#4	"Neoplasms"[Mesh]	4,109,175
#5	Cancer *OR Malign*[Title/Abstract] OR Carcinoma*[Title/Abstract] OR Lymphoma*[Title/Abstract] OR Melanoma*[Title/Abstract] OR Neuroblastoma*[Title/Abstract] OR Neoplasm*[Title/Abstract] OR Sarcoma*[Title/Abstract] OR tumor* OR tumor*[Title/Abstract] OR end-of-life[Title/Abstract]	3,584,978
#6	#4 OR #5	5,258,556
#7	experience*[Title/Abstract] OR opinion*[Title/Abstract] OR view*[Title/Abstract] OR perspective*[Title/Abstract] OR attitude*[Title/Abstract] OR perception*[Title/Abstract] OR reflect*[Title/Abstract] OR understand*[Title/Abstract] OR respect*[Title/Abstract]	8,222,756
#8	Physician*[Title/Abstract] OR Doctor*[Title/Abstract] OR Nurse*[Title/Abstract] OR Health care professional*[Title/Abstract] OR Health care worker*[Title/Abstract] OR Healthcare professional*[Title/Abstract] OR Healthcare worker*[Title/Abstract] OR Nursing staff[Title/Abstract] OR Medical staff[Title/Abstract] OR Community Health Worker*[Title/Abstract] OR Social Work*[Title/Abstract] OR Formal care*[Title/Abstract] OR stakeholder*[Title/Abstract] OR carer*[Title/Abstract]	1,169,347
#9	#7 AND #8	486,708
#10	Relative*[Title/Abstract] OR famil*[Title/Abstract] OR Next of kin*[Title/Abstract] OR Spouse*[Title/Abstract] OR Informal carer*[Title/Abstract] OR Caregiver*[Title/Abstract] OR Sibling*[Title/Abstract] OR Significant other*[Title/Abstract] OR neighbor*[Title/Abstract] OR neighbor*[Title/Abstract] OR themselves[Title/Abstract] OR own[Title/Abstract] OR patient*[Title/Abstract] OR client*[Title/Abstract] OR citizen*[Title/Abstract] OR people[Title/Abstract] OR peoples[Title/Abstract]	12,157,991
#11	#7 AND #10	3,820,615
#12	#9 OR #11	3,963,978
#13	((((((("Activities of Daily Living"[Mesh]) OR "Patient Participation"[Mesh]) OR "Social Stigma"[Mesh]) OR "Decision Making, Shared"[Mesh]) OR "Palliative Care"[Mesh]) OR "Information Dissemination"[Mesh]) OR "Consumer Health Information"[Mesh]	275,204
#14	everyday Life[Title/Abstract] OR encount*[Title/Abstract] OR involvement[Title/Abstract] OR daily living[Title/Abstract] OR ADL[Title/Abstract] OR participat*[Title/Abstract] OR shared decision making[Title/Abstract] OR relationship*[Title/Abstract] OR interaction*[Title/Abstract] OR communicat*[Title/Abstract] OR informati*[Title/Abstract] OR activit*[Title/Abstract] OR discrimination*[Title/Abstract] OR stigma*[Title/Abstract] OR prejudice*[Title/Abstract] OR interpersonal relation*[Title/Abstract] OR community adaptation*[Title/Abstract] OR psychological[Title/Abstract] OR dissemination[Title/Abstract] OR consumer health[Title/Abstract] OR life experience*[Title/Abstract] OR involv*[Title/Abstract] OR coping*[Title/Abstract] OR cope*[Title/Abstract] OR care trajector*[Title/Abstract] OR health care[Title/Abstract] OR healthcare[Title/Abstract] OR palliative care[Title/Abstract] OR end-of-life[Title/Abstract] OR barrier*[Title/Abstract] OR obstacle*[Title/Abstract] OR facilitat*[Title/Abstract]	12,575,586
#15	#13 OR #14	12,668,014
#16	#3 AND #6 AND #12 AND #15	1,209
#17	Filters: Danish, English, Norwegian, Swedish, Hebrew, from 2005 to 2025	**1,039**
Embase		
#1	'learning disorder'/exp OR 'down syndrome'/exp OR 'mental deficiency'/exp OR 'intellectual disabilit*':ti,ab,kw OR id:ti,ab,kw OR 'learning disabilit*':ti,ab,kw OR 'mental retard*':ti,ab,kw OR 'down syndrome':ti,ab,kw OR 'developmental disabilit*':ti,ab,kw OR 'mental deficien*':ti,ab,kw OR 'learning disorder*':ti,ab,kw	349,664
#2	'neoplasm'/exp OR 'neoplasm' OR cancer*:ti,ab,kw OR malign*:ti,ab,kw OR carcinoma*:ti,ab,kw OR lymphoma*:ti,ab,kw OR melanoma*:ti,ab,kw OR neuroblastoma*:ti,ab,kw OR neoplasm*:ti,ab,kw OR sarcoma*:ti,ab,kw OR 'tumor* ot tumor*':ti,ab,kw OR 'end of life':ti,ab,kw	7,569,021
#3	physician*:ti,ab,kw OR doctor*:ti,ab,kw OR nurse*:ti,ab,kw OR 'health care professional*':ti,ab,kw OR 'health care worker*':ti,ab,kw OR 'healthcare professional*':ti,ab,kw OR 'healthcare worker*':ti,ab,kw OR 'nursing staff':ti,ab,kw OR 'medical staff':ti,ab,kw OR 'community health worker*':ti,ab,kw OR 'social work*':ti,ab,kw OR 'formal care*':ti,ab,kw OR stakeholder*:ti,ab,kw OR carer*:ti,ab,kw) AND (experience*:ti,ab,kw OR opinion*:ti,ab,kw OR view*:ti,ab,kw OR perspective*:ti,ab,kw OR attitude*:ti,ab,kw OR perception*:ti,ab,kw OR reflect*:ti,ab,kw OR understand*:ti,ab,kw OR respect*:ti,ab,kw	703,202

(Continued)

TABLE 2 (Continued)

Search	Search terms	Results
#4	relative*:ti,ab,kw OR famil*:ti,ab,kw OR 'next of kin*':ti,ab,kw OR spouse*:ti,ab,kw OR 'informal carer*':ti,ab,kw OR caregiver*:ti,ab,kw OR sibling*:ti,ab,kw OR 'significant other*':ti,ab,kw OR neighbor*:ti,ab,kw OR neighbor*:ti,ab,kw OR themselves:ti,ab,kw OR patient*:ti,ab,kw OR client*:ti,ab,kw OR citizen*:ti,ab,kw OR people*:ti,ab,kw) AND (experience*:ti,ab,kw OR opinion*:ti,ab,kw OR view*:ti,ab,kw OR perspective*:ti,ab,kw OR attitude*:ti,ab,kw OR perception*:ti,ab,kw OR reflect*:ti,ab,kw OR understand*:ti,ab,kw OR respect*:ti,ab,kw	5,664,817
#5	#3 OR #4	5,842,238
#6	'daily life activity'/exp OR 'participation'/exp OR 'shared decision making'/exp OR 'stigma'/exp OR 'community adaptation' OR 'information dissemination'/exp OR 'consumer health information'/exp OR 'care trajectories' OR 'palliative therapy'/exp OR 'everyday life':ti,ab,kw OR encount*:ti,ab,kw OR involvement:ti,ab,kw OR 'daily living':ti,ab,kw OR adl:ti,ab,kw OR participat*:ti,ab,kw OR 'shared decision making':ti,ab,kw OR relationship*:ti,ab,kw OR interaction*:ti,ab,kw OR communicat*:ti,ab,kw OR informati*:ti,ab,kw OR activit*:ti,ab,kw OR discrimination*:ti,ab,kw OR stigma*:ti,ab,kw OR prejudice*:ti,ab,kw OR 'interpersonal relation*':ti,ab,kw OR 'community adaptation*':ti,ab,kw OR psychological:ti,ab,kw OR dissemination:ti,ab,kw OR 'consumer health':ti,ab,kw OR 'life experience*':ti,ab,kw OR involv*:ti,ab,kw OR coping*:ti,ab,kw OR cope*:ti,ab,kw OR 'care trajector*':ti,ab,kw OR 'health care':ti,ab,kw OR healthcare:ti,ab,kw OR 'palliative care':ti,ab,kw OR 'end of life':ti,ab,kw OR barrier*:ti,ab,kw OR obstacle*:ti,ab,kw OR facilitat*:ti,ab,kw	15,892,011
#7	#1 AND #2 AND #5 AND #6	4,658
#8	#7 AND ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)	2,142
#9	#7 NOT #8	2,516
#10	#7 NOT #8 AND [01-01-2005]/sd NOT [01-06-2025]/sd	2,208
#11	#10 AND [embase]/lim;Language: Danish, English, Norwegian, Hebrew	**1,799**
CINAHL		
#1	(MH "Intellectual Disability+") OR TI (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*) OR AB (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*)	78,677
#2	(MH "Neoplasms+") OR TI (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life) OR AB (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life)	945,776
#3	TI (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*) OR AB (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*)	1,752,427
#4	TI (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples) OR AB (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples)	2,980,648
#5	TI (Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*) OR AB (Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*)	799,760
#6	#3 AND #4	1,003,381
#7	#3 AND #5	326,744
#8	#6 OR #7	1,113,702
#9	((MH "Activities of Daily Living+") OR (MH "Patient Participation+") OR (MM "Decision Making, Shared") OR (MM "Stigma") OR (MH "Interpersonal Relations+") OR (MM "Selective Dissemination of Information") OR (MH "Consumer Health Information+") OR (MM "Palliative Care")) OR TI (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*) OR AB (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*)	2,643,058
#10	#1 AND #2 AND #8 AND #9	527
#11	S10 Limiters - Publication Date: 20050101-20250531;Language: Danish, English, Norwegian, Hebrew, Norwegian, Chinese	**497**

(Continued)

TABLE 2 (Continued)

Search	Search terms	Results
PsycInfo		
#1	DE "Intellectual Development Disorder" OR TI (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*)) OR AB (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*))	130,349
#2	DE "Neoplasms" OR TI (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life) OR AB (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life)	102,993
#3	TI (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*) OR AB (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*)	2,461,712
#4	TI (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples) OR AB (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples)	193,254
#5	TI (Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*) OR AB (Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*)	491,034
#6	#3 AND #4	1,041,167
#7	#3 AND #5	291,911
#8	#6 OR #7	1,161,653
#9	((((((DE "Activities of Daily Living") OR (DE "Client Participation")) OR (DE "Shared Decision Making")) OR (DE "Stigma" OR DE "Mental Health Stigma" OR DE "Self-Stigma")) OR (DE "Discrimination")) OR (DE "Palliative Care")) OR TI (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*) OR AB (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*)	3,218,053
#10	#1 AND #2 AND #8 AND #9	325
#11	#10 Limiters-Publication Year: 2005–2025; ; Language: Swedish, English, Hebrew, Danish, Norwegian, Chinese	**298**
ERIC		
#1	DE "Intellectual Disability" OR TI (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*) OR (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*)	86,372
#2	TI (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life) OR AB (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life)	3,009
#3	TI (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*) OR AB (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*)	837,495
#4	TI (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples) OR AB (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples)	419,220
#5	TI (Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*) OR AB (Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*)	127,617
#6	#3 AND #4	209,213
#7	#3 AND #5	72,437

(Continued)

TABLE 2 (Continued)

Search	Search terms	Results
#8	#6 OR #7	255,085
#9	TI (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*) OR AB (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*)	1,047,441
#10	#1 AND #2 AND #8 AND #9	73
#11	Limiters-Published Date: 20050101–20250531; Language: English	**69**
SocIndex		
#1	DE "INTELLECTUAL disabilities" OR TI (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*) OR AB (Intellectual disabilit* OR ID OR Learning disabilit* OR mental retard* OR Down syndrome OR developmental disabilit* OR mental deficien* OR learning disorder*)	17,251
#2	TI (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life) OR AB (Cancer* OR Malign* OR Carcinoma* OR Lymphoma* OR Melanoma* OR Neuroblastoma* OR Neoplasm* OR Sarcoma* OR tumor* OT tumor* OR end-of-life)	25,367
#3	TI (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*) OR AB (experience* OR opinion* OR view* OR perspective* OR attitude* OR perception* OR reflect* OR understand* OR respect*)	945,788
#4	TI (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples) OR AB (Relative* OR famil* OR Next of kin* OR Spouse* OR Informal carer* OR Caregiver* OR Sibling* OR Significant other* OR neighbor* OR neighbor* OR themselves OR patient* OR client* OR citizen* OR people* OR peoples)	808,539
#5	TI ((Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*) OR AB ((Physician* OR Doctor* OR Nurse* OR Health care professional* OR Health care worker* OR Healthcare professional* OR Healthcare worker* OR Nursing staff OR Medical staff OR Community Health Worker* OR Social Work* OR Formal care* OR stakeholder* OR carer*)	262,014
#6	#3 AND #4	346,697
#7	#3 AND #5	123,706
#8	#6 OR #7	409,365
#9	((((((DE "EVERYDAY life" OR DE "ACTIVITIES of daily living") OR (DE "ACTIVITIES of daily living")) OR (DE "PARTICIPATION")) OR (DE "INTERPERSONAL relations")) OR (DE "SOCIAL stigma")) OR (DE "PALLIATIVE treatment")) OR TI (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*) OR AB (everyday Life OR encount* OR involvement OR daily living OR ADL OR participat* OR shared decision making OR relationship* OR interaction* OR communicat* OR informati* OR activit* OR discrimination* OR stigma* OR prejudice* OR interpersonal relation* OR community adaptation* OR psychological OR dissemination OR consumer health OR life experience* OR involv* OR coping* OR cope* OR care trajector* OR health care OR healthcare OR palliative care OR end-of-life OR barrier* OR obstacle* OR facilitat*)	1,146,791
#10	#1 AND #2 AND #8 AND #9	30
#11	#10 Limiters-Publication Date: 20050101–20250531; Language: Swedish, Danish, English, Hebrew, Norwegian, Chinese	**25**

The bold numbers indicate the total number of articles retrieved from each database for the initial screening.

with ID and cancer continued their everyday life as much as possible (28, 30).

Some individuals with ID and cancer actively employed personal coping strategies, including self-talk for reassurance or speaking to a deceased loved one (e.g., a mother), or drawing strength from religious faith and prayer (27). From the perspective of individuals with ID and cancer, support from relatives played an essential role in allowing them to cope with both treatment periods and end-of-life stages (27, 32, 33). However, some became aware of the burden their helplessness imposed on others and felt concerned about it (28, 33). Often, they valued time with family and offered comfort to others, even while facing their

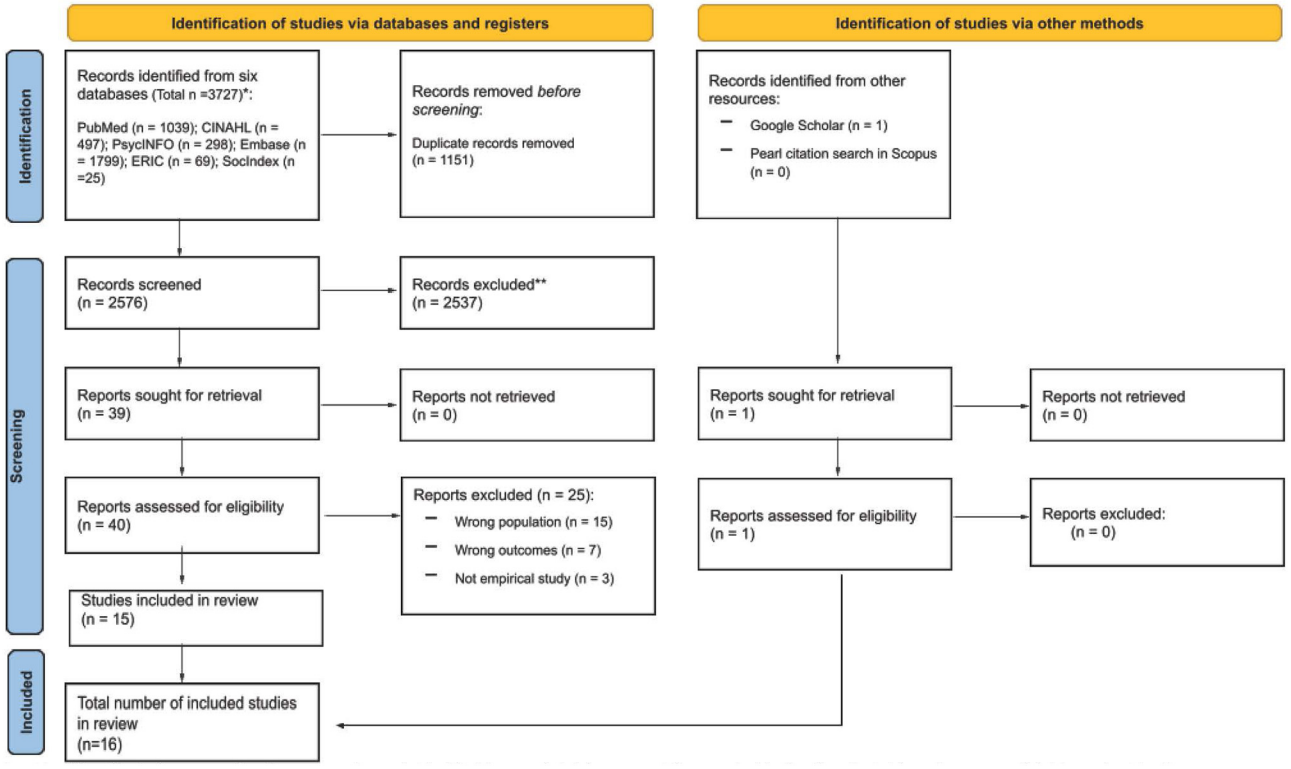

FIGURE 1
PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources. Flowchart displaying the study selection process. Records from databases and other sources are identified, with duplicates removed. Records screened total two thousand five hundred seventy-six, with two thousand five hundred thirty-seven excluded. Forty reports are assessed, fifteen included in review. Total included studies: sixteen. Source: (73). This work is licensed under CC BY 4.0. To view a copy of this license, visit https://creativecommons.org/licenses/by/4.0/.

own struggles (28). Some continued the activities they loved and used to do as a main coping strategy during treatment or at the end of life (27, 30, 31, 33). Previous life experiences with illness and death of significant others and the ability to live in the moment supported the coping of individuals with mild to severe ID (27, 32). Cancer brought new experiences of dependency, yet many individuals with ID were already familiar with relying on others, which contributed to their calm acceptance of the situation (30, 32).

Some individuals with ID and cancer found it difficult to cope with bodily changes, such as smells, and treatment side effects, such as hair loss, diarrhea and vomiting (27, 28, 30). It was sometimes followed by a feeling of embarrassment. One example was a person who, after being discharged from hospital, vomited in the street and saw people on a bus looking at him and laughing. He thought they assumed he was drunk (28). From relatives' and professionals' perspectives, individuals with ID and cancer experienced marked decline in physical functioning during treatment, becoming increasingly dependent due to worsening health and, in some cases, immobility. They coped by accepting the assistance they needed (36). For some, cancer served as a turning point that fostered autonomy and assertiveness, as they actively sought information and voiced their needs, encouraged by supportive professionals (40). Others had the ability to make shifts in daily priorities, leading to greater appreciation for small daily joys (27).

Balancing the right to information and the limits of communication abilities

Individuals with severe/profound ID were usually not told their diagnosis, while those with mild/moderate ID were given information but often lacked the full details or adequate support needed to understand it (26, 30, 32, 33, 36). Individuals with ID who received information respond to their cancer in various ways. Some asked for taking part in others' cancer stories that made them laugh and cry, told in a simple and understandable way (28). Other individuals with ID received full disclosure about their cancer (26, 27, 32). One example was a woman with breast cancer, fully informed by her general practitioner, chose to decline further treatment because she hated hospitals and needles (26). Another example was a young man with testicular cancer, who was informed about chemotherapy and accepted treatment, requested by his mother, on behalf of him (38). From the perspective of professionals and relatives, the young man was primarily reliant on a wheelchair, exhibited minimal verbal communication, and lacked an effective means of expressing pain. Nonetheless, he could use simple signs

TABLE 3 Study characteristics.

Author(s), year of publication (country)	Journal	Study aim	Design; analytical method	Study population; recruitment setting	Study period	Main findings
Bekkema, N., de Veer, A. J., Hertogh, C. M., and Francke, A. L., 2014 (Netherlands) (36)	Journal of Intellectual Disability Research	To describe how caregivers and relatives shape respect for autonomy in the end-of-life care for people with ID and to discuss to what extent this corresponds with a relational concept of autonomy	Individual in-depth semi-structured interviews; Thematic analysis	7 relatives, 15 health- and social care professionals and 2 volunteers related to 6 recently deceased people with ID and cancer + 7 relatives, and 16 health- and social care professionals related to 6 recently deceased people with ID and other diseases; 10 ID care provider organizations in different parts of the Netherlands	December 2010–April 2011	Individuals with ID were often excluded from cancer-related communication and decision-making. Relatives struggled to balance protection with autonomy. While people with mild ID could express preferences, support was essential.
Bernal, J. and Tuffrey-Wijne, I., 2008 (United Kingdom) (26)	International Journal on Disability and Human Development	To explore issues around disclosure and information about diagnosis and prognosis for people with intellectual disabilities who have cancer	Literature review and selected empirical material from an ethnographic study; N/A	13 individuals with ID and cancer; N/A	N/A	Relatives and professionals faced challenges in communicating cancer diagnoses to individuals with intellectual disabilities, often withholding information based on assumptions about their ability to understand. While some individuals benefited from honest and clear communication, others coped by focusing on the present. There was an ethical tension between protection, autonomy, and the need for tailored communication strategies.
Cresswell, A. and Tuffrey-Wijne, I., 2008 (United Kingdom) (27)	British Journal of Learning Disabilities	To describe the experience of a person with ID who have lymphoma	Case from ethnographic study–narrative; narrative case description	1 individual with ID and cancer; N/A	N/A	Individuals with ID described cancer as frightening and confusing, worsened by poor communication and lack of clear explanations. Maintaining routines, emotional support, and faith helped them cope. Tailored communication, empathy, and accessible resources were essential.
Delany, C., Diocera, M., and Lewin, J. , 2023 (Australia) (38)	Journal of Intellectual and Developmental Disability	To explore how can health practitioners ensure the functional and cognitive effects of a patient's disability are considered and balanced when identifying likely burdens, risks and benefits of cancer treatment	Case study; narrative case description	3 healthcare professionals' perspective about one individual with ID and metastatic testicular cancer; Oncological department, hospital	N/A	Standard cancer treatment might be unsuitable for individuals with ID due to limited capacity to tolerate or understand procedures, but a modified plan was developed to balance treatment benefits with patient wellbeing.
Jones, A., Tuffrey-Wijne, I., Bernal, J., Butler, G. and, Hollins, S., 2007 (United Kingdom) (34)	British Journal of Learning Disabilities	To explore how people with ID accessed and were supported to use a pictorial cancer information book.	Non-participant observations; Thematic analysis.	1 individual with ID and cancer, 4 individuals with ID who had lost a parent in cancer, 5 paid caregivers/supporters; the National Network for the Palliative Care of People with Learning Disabilities and professional contacts of the authors	N/A (authors' note: after 2003, before 2007)	Relatives faced communication challenges while assisting individuals with ID and cancer. They felt excluded from medical information and had to independently seek resources.

(Continued)

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TABLE 3 (Continued)

Author(s), year of publication (country)	Journal	Study aim	Design; analytical method	Study population; recruitment setting	Study period	Main findings
Flynn, S., Hulbert-Williams, N. J., Hulbert-Williams, L., and Bramwell, R., 2016 (United Kingdom) (37)	Psycho-Oncology	To understand the experiences of this population from multiple perspectives, generating theory and further research questions.	Semi-structured interviews; grounded theory.	6 individuals with ID and cancer, 4 relatives, 8 healthcare professionals; Coordinators in oncology and ID settings	N/A	Individuals with ID often faced communication barriers that led to confusion, limited understanding, and emotional disengagement during cancer care. When supported with clear, compassionate communication, they could meaningfully engage and cope well.
Martean, M. H., Dallos, R., Stedmon, J., and Moss, D., 2013 (United Kingdom) (40)	British Journal of Learning Disabilities	To explore the lived and told experience of a person with intellectual disability, who has been given a diagnosis of breast cancer	Case study based on interviews; Narrative analysis	1 individual with ID and cancer; An Oncology Center	N/A	An individual with ID and cancer narrated her own story. Despite early confusion and marginalization, she developed a positive outlook, reframed her narrative, and grew in confidence and self-expression after being diagnosed with cancer. She expressed the need for supportive environments and the importance of accessible, person-centered communication.
Moore, C. M., and Kates, J., 2022 (United States of America) (39)	Journal of Hospice and Palliative	To explore the complexities and unique considerations in ensuring ethical and practical end-of-life care for people with IDs.	A blended case study; Narrative case description	2 healthcare professionals' perspective on one individual with ID and metastatic cancer; N/A	N/A	Relatives emphasized the importance of daily routines and familiar comforts in helping individuals with ID cope with cancer. Individuals with ID and cancer expressed clear end-of-life wishes, including staying at home. Collaborative support from relatives and professionals could help to enable a peaceful, dignified death in a familiar environment for individuals with ID and cancer.
Tuffrey-Wijne, I., Bernal, J., Jones, A., Butler, G., and Hollins, S., 2006 (United Kingdom) (35)	European Journal of Oncology Nursing	To explore the information needs of people with ID who are affected by cancer.	Observation and tape-recordings of the use of a pictorial cancer information book designed for people with ID, and semi-structured interviews; Thematic analysis	1 individual with ID and cancer, 4 individuals with ID who had lost a parent in cancer, 5 paid carers/supporters; the authors' nation-wide professional networks and personal contact	N/A	Relatives and professionals used a picture-based book as an accessible tool to support individuals with ID and cancer in understanding treatment and expressing emotions. Individuals with ID and cancer expressed a need for more detailed and varied resources to fully address their questions and diverse experiences with cancer.
Tuffrey-Wijne, I. and Davies, J., 2007 (United Kingdom) (28)	British Journal of Learning Disabilities	To explore the experiences of people with learning disabilities who have cancer	Case from ethnographic study; Narrative case description	1 individual with ID and penile cancer; N/A	2005–2008	Individuals with ID experienced fear, shame, and emotional isolation when facing cancer. Delayed help-seeking, difficulty expressing symptoms, and coping silently were common. Individuals with ID and cancer emphasized the need for early intervention, honest communication, emotional support, and accessible cancer education.

(Continued)

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TABLE 3 (Continued)

Author(s), year of publication (country)	Journal	Study aim	Design; analytical method	Study population; recruitment setting	Study period	Main findings
Tuffrey-Wijne, I., Curfs, L. and Hollins, S. 2008 (United Kingdom) (30)	International Journal on Disability and Human Development	To explore the issues that affect the delivery of optimal palliative care to people with ID who have cancer.	Case from ethnographic study; Narrative case description	1 individual with ID and lung cancer; N/A	N/A	Relatives of individuals with ID and cancer faced challenges in communication, emotional support, and end-of-life care. Individuals with ID and cancer might not grasp their diagnosis, showing passive coping. Relatives emphasized the importance of maintaining routine and comfort for individuals with ID and cancer but often felt unprepared for rapid decline.
Tuffrey-Wijne, I., 2009a (United Kingdom) (29)	End of Life Care	From the perspective of the researcher, to describe some of the suffering of two women who had learning disabilities and were dying of cancer.	Cases from ethnographic study; Narrative case description	2 individuals with ID and lung cancer; N/A	N/A—3-years study period	Several individuals with ID and cancer hid their distress, felt pressure to appear cheerful. Their emotional pain was often overlooked, while relatives struggled to interpret and respond to unspoken suffering.
Tuffrey-Wijne, 2009b (United Kingdom) (30)	Learning Disability Practice	To explore the factors that influence where people with learning disabilities are cared for at the end of life, and where they die.	Cases from ethnographic study; Narrative case description	2 individuals with ID and lung cancer; N/A	N/A—3-years study period	Individuals with ID and cancer often lived highly dependent lives, with others managing decisions and care for them. They faced pain, confusion, and disruptions to routine, sometimes without full understanding. Relatives struggled to meet emotional and practical needs. The meaning of "home" shaped end-of-life experiences, dignity, and feelings of safety.
Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G., and Hollins, S., 2009 (United Kingdom) (31)	The British Journal of General Practice	To explore the experiences and needs of people with ID who have cancer, to gain insight into their lives, the impact of cancer, the way they experienced care, and any barriers they faced in accessing health care.	Ethnographic study, mainly participant observation; Grounded theory	13 individuals with ID and cancer; N/A	N/A	Individuals with ID and cancer often lived highly dependent lives, which were shaped by others' decisions and limited autonomy. Many experienced late diagnoses, inadequate pain management, and exclusion from communication about their illness. Relatives often lacked training and confidence. Individuals with ID and cancer often experienced emotions deeply but struggled to express them clearly or be fully understood by others. Some found comfort in supportive environments, routines, and close relationships near the end of life.

(Continued)

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TABLE 3 (Continued)

Author(s), year of publication (country)	Journal	Study aim	Design; analytical method	Study population; recruitment setting	Study period	Main findings
Tuffrey-Wijne, I., Bernal, J., and Hollins, S., 2010a (United Kingdom) (32)	European Journal of Oncology Nursing	To explore how much people with intellectual disabilities who have cancer understand about their diagnosis and prognosis, and to explore how much they are told about their cancer.	Ethnographic study; Grounded theory	13 individuals with ID and cancer; N/A	N/A—3-years study period	Most individuals with ID were told they had cancer, but few fully understood its implications. Understandings were often limited by relatives' decisions to withhold information, use of complex medical language, or communication challenges. Some individuals with ID coped well with cancer when given clear and honest explanations, while others were shielded from the truth due to their relatives' beliefs about their ability to understand.
Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G., and Hollins, S., 2010b (United Kingdom) (33)	Nursing Times	To explore the experiences of people with learning disabilities who had cancer, from their own perspectives	Ethnographic study, using participant observations; Grounded theory	13 individuals with ID and cancer; N/A	N/A	Individuals with ID and cancer lived deeply dependent lives, with others often making key decisions for them, including about truth-telling and treatment. Access to care for people with ID and cancer often depended on relatives and/or professionals noticing symptoms and advocating for help. However, those providing support frequently lacked training and resources. Despite facing loneliness, misunderstanding, and a history of trauma, many individuals with ID showed resilience, drawing strength from familiar routines, trusted relationships, and close family connections, especially in their final days.

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TABLE 4 Qualitative study appraisal*.

Author(s), years	Section A: Are the results valid?						Section B: What are the results?			Section C: Will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
Bekkema et al., 2014 (36)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Bernal and Tuffrey-Wijne, 2008 (26)	Yes	Yes	Yes	Cannot tell	Cannot tell	Cannot tell	Cannot tell	Yes	Yes	Yes	8
Cresswell and Tuffrey-Wijne, 2008 (27)	Yes	Cannot tell	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	9
Delany et al., 2023 (38)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9.5
Flynn et al., 2016 (37)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Jones et al., 2007 (34)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Martean et al., 2013 (40)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Moore and Kates, 2022 (39)	Yes	Yes	Yes	N/A	Yes	Cannot tell	Yes	Yes	Yes	Yes	9.5
Tuffrey-Wijne et al., 2006 (35)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Tuffrey-Wijne and Davies, 2007 (28)	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	9.5
Tuffrey-Wijne et al., 2008 (30)	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	9
Tuffrey-Wijne et al., 2009 (31)	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	9.5
Tuffrey-Wijne et al., 2010a (32)	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	9.5
Tuffrey-Wijne et al., 2010b (33)	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	9.5

*Conducted in accordance with CASP Qualitative study checklist (24).

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and gestures. Family members and professionals collaborated to support the use of non-verbal communication tools, mobility aids, bed management, and recommendations for toileting and feeding, to ensure the success of the curative chemotherapy course, carried out under anesthesia (38).

From the perspective of relatives, individuals with ID had the right to be informed, but it was usually the relatives who received the prognosis first (34, 36, 38). In cases of severe ID, their understanding was often unclear, making it difficult to assess their need for information. Sometimes, no communication occurred at all, as it was seen as impossible due to low cognitive ability (36). Some lacked the verbal ability to express their understanding or ask questions, while others either received answers that obscured the truth or chose not to ask at all (32, 33). An example, from the professionals' perspective, was a person who was not concerned about what the doctor would say or what might happen to him. Instead, he was more worried that the appointment was taking too long and interfering with his usual routines, like watching videos or having lunch on time (32). Only a few posed follow-up questions to their doctor and received support in understanding the implications of their diagnosis (33). Communication barriers with healthcare professionals frequently left individuals with ID confused about their health, leading to anxiety in their care experience (33, 37).

The lack of information and use of unfamiliar language in hospitals made some individuals with ID feel scared and confused about what was happening (26, 27, 31, 32, 37). Individuals with ID sometimes misunderstood bad news, interpreting it as good news (32). Some individuals with ID felt supported with information about, for example, radiotherapy and being able to express their own symptoms, such as fatigue, by using a picture book illustrating the treatment and its side effects (35).

Professionals differed in their assessments of how well individuals with ID could understand information about their disease. For example, a general practitioner informed a person that he had cancer but assessed that he did not appear to grasp what was being said. However, afterwards, his caregiver felt able to explain why he was becoming so tired and breathless, interpreting that he understood a little more each time and showed no signs of distress when being told (26). Other individuals with ID fully understood the necessity of being treated with chemotherapy to be cured, where life experiences with family members having cancer and receiving treatment also supported their understanding (27). Relatives and professionals observed that, with time and support, individuals with ID and cancer could express what mattered to them and adapt to changes, underscoring the importance of recognizing their communicative abilities (36).

Encountering death in various ways

From professionals' perspective, some individuals with mild ID could express and revise their last wishes during their cancer journey, often with support by, for example, completing a book outlining preferences such as the funeral location or coffin color (36). In contrast, from professionals' perspective, individuals with severe ID often had unclear or unknown end of life wishes and were not involved in end-of-life decisions such as starting life-prolonging treatment or moving to another place (29, 32, 36). Decisions were thus made by relatives and professionals based on what they believed to be the best interests for individuals with severe ID and cancer (32). Wishes were sometimes discussed beforehand, but in other cases, individuals with ID and cancer were only informed after the decision, such as the use of a feeding tube or relocation (29–31, 33, 36). Others were involved but did not understand the information, while some understood that they were approaching death based on their previous life experiences (26, 29, 32, 39). Relatives and professionals observed that individuals with severe ID showed a greater desire and ability to express themselves during the final stage of life than in earlier stages of cancer. Through life, some had learned to conceal pain and distress. For example, one man with a history of childhood suffering from foot deformities rarely complained, even in the final, weakening stages of cancer (33).

From the perspective of relatives and professionals, when communication was possible, some individuals with ID and cancer shared concrete and specific end-of-life wishes, such as the preference of place to die. One example was a man with cancer who expressed that it was most valued to him to stay at home rather than in a hospital. He wanted to be with his friends and favorite fish, and his wish was fully supported by family and professionals (39). According to relatives and professionals, some individuals with ID and cancer also remained cheerful throughout their terminal illness and experienced a good death. During this life phase, their everyday life was supported to continue familiar and meaningful activities, such as being surrounded by lights and music, attending the day center, and meeting friends (30, 31, 33, 39). From the professionals' perspective, supporting a good death for individuals with ID involved various approaches, which not only met medical needs but also preserved comfort and familiarity in their everyday lives during the final phase (26, 36, 39). For example, although some individuals with ID wished to and died in their own apartments/residential homes (31–33, 36), this was not always feasible from a professional perspective, because a transition from hospital back to home could cause additional suffering, including sadness or depression (36). To help individuals feel more comfortable, healthcare professionals sometimes hung pictures of the person's apartment in the hospital room or returned the body to their apartment after death, maintaining a connection with their everyday environment and respecting the spirit of the deceased (36). From professionals' perspectives, individuals with ID and cancer were often relocated to nursing homes or hospices during the final phase of life to ensure safe, reassuring daily comfort and care, while also protecting the wellbeing of cohabitants in residential homes (31–33). In other cases, professionals supported individuals' wishes to die at home, either alone or with care from relatives and staff, based on what was feasible and perceived as respectful to the person's familiar routines and preferences (31, 39). Others died at hospital (31, 32). There

were also examples of persons who died in an ambulance (30, 31). Some individuals with ID appeared to face their final decline with calm acceptance and grace (32), others were screaming loudly (33) or expressed intolerable physical and emotional pain (31).

Discussion

The discussion will focus on three main findings, namely (1) individuals with ID often demonstrated an ability to live in the moment, which proved to be a strength in both living with and dying from cancer, (2) the disconnect between the right to receive information about cancer diagnosis, treatment, and prognosis, and the diverse capacities to comprehend it, and (3) only the voices of 22 individuals with ID and cancer have been heard in the included studies. Furthermore, the strengths and limitations of the study's method will be discussed.

The results pointed to the fact that individuals with ID often demonstrated an ability to live in the moment as a coping strategy and strength in living and dying with cancer. This present-moment awareness involves fully engaging with and appreciating the current experience, without being distracted by past regrets or future concerns. Today, this ability is often associated with mindfulness (41). It seems that individuals with ID may have mindfulness as an incorporated way of living, in contrast to the modern medico-psychological trend of 'cultivating' mindfulness as a therapeutic technique for managing biopsychosocial conditions (42, 43). Living in the moment serves as an effective coping strategy for individuals facing life-threatening diseases, often achieved through small, everyday pleasures that added meaning to their lives (44). Research suggests that maintaining daily routines can serve as a source of strength, helping individuals with ID to stay focused on the present moment, preserve a sense of self and autonomy, and promote wellbeing in the context of advanced disease, also in the end of life (45). This calls for a shift away from a medico-deficit-based view of individuals with ID toward recognizing and building on individuals existing strengths and resources. However, implementing such approaches in practice is challenging, as individuals with ID and their relatives often experience tensions between supporting independence through daily routines and securing appropriate medical care (46). Structured support systems, on which many rely, often lack flexibility to accommodate individualized routines (47). This highlights the importance of developing flexible, person-centered approaches in healthcare that accommodate and support individuals with ID living and dying with cancer.

Furthermore, the results revealed a disconnect between individuals' right to receive information about a cancer diagnosis, treatment, and prognosis, and their diverse capacities to comprehend it. Some individuals were fully informed and understood. Others received only partial information and/or had limited understanding. In some cases, individuals with ID were not informed at all. Frequently, relatives received information before the patient, even though it was the patient whom the matter directly concerned. Consistent with current findings, research shows that many individuals with ID experience stress in healthcare settings due to communication barriers and difficulty processing medical information. Often, they struggle to report symptoms or recall visits and some express discomfort through behaviors like screaming, aggression, or hyperactivity (48). Inadequate provision of information and understanding can contribute to poorer symptom control, reduced access to palliative care, and increased risk of a painful or undignified death among individuals with ID (49, 50). Therefore, withholding information about diagnoses, treatment, and prognosis from individuals with ID must be considered unethical and paternalistic in healthcare. Similarly, informing relatives without involving individuals with ID and cancer must also be regarded as unethical and paternalistic, unless the person has given their consent (48, 51). Such practices fundamentally contradict human rights. Human rights and healthcare for people with ID are deeply interconnected. The right to the highest attainable standard of health, free from discrimination because of disability, is a fundamental human right, firmly established in international human rights law, including the Convention on the rights of persons with disabilities (CRPD) (52). The CRPD obliges States Parties to ensure that persons with disabilities have access to the same range, quality, and standard of healthcare as others. It also underscores the importance of bodily autonomy, which is the right to make informed decisions about one's own body and health, including access to information, services, and the means to act on these decisions without discrimination, coercion, or violence. The current literature review calls for future research on inclusive information practices that ensure not only access to information but also comprehension. As Bateson (53) noted, information is a difference that makes a difference, pointing to that information is only given when it is understood.

Research reveals that relatives often decide whether to involve individuals with ID during cancer treatment based on their perceptions of that person's capacity or incapacity (18). However, individuals with ID should have the right to decide how much information they wish to receive. Relatives may sometimes be less willing to disclose this information, possibly driven by the intention of 'protecting' individuals with ID, or they do not know how to effectively communicate the information (54). Healthcare professionals are accustomed to interacting with people who have communication difficulties, such as individuals with stroke, aphasia, brain tumors, deafness, or dementia, as well as those who speak other languages, such as immigrants and refugees. All these communication experiences and already well-known techniques can also be applied when engaging with individuals with ID. Research suggests asking individuals with ID to clarify questions, using visual aids or pictures, clearly explaining options, and discussing possible outcomes could support informed understanding and engagement (55). To help individuals with ID to understand healthcare information, studies show the importance of involving relatives to help translate and adapt information in ways that are understandable for individuals with ID. However, this requires that healthcare professionals are also attentive to the distinct needs of relatives, such as trustworthiness and clear information, in their encounters with individuals with ID and their relatives (56, 57).

Only the voices of 22 individuals with ID and cancer have been heard in the included studies, whereas all were from the United Kingdom and the newest publication was from 2016. Many research projects exclude people with ID, especially those with

moderate to severe ID, due to research design, capacity issues, and inadequate inclusion methods (58, 59). The voices of individuals with ID and cancer remain significantly underrepresented in research. A clear knowledge gap persists regarding their lived experiences, particularly when expressed directly by the individuals themselves. This silence calls for urgent efforts to amplify their narratives and promote inclusive research practices. A similar lack of representation is evident among individuals with severe mental illness who also face cancer diagnoses (60, 61). Exclusion of these individuals from health research is often driven by pervasive stereotypes and paternalistic attempts to protect those considered as 'vulnerable.' It is important not to diagnose groups of people as vulnerable, but instead to focus on the fact that people are often capable and resourceful, though they can be in vulnerable situations, such as when facing cancer, approaching death, or experiencing loss (62, 63). Furthermore, many researchers lack the necessary knowledge and skills to effectively include these individuals in studies. Healthcare professionals and researchers often underestimate the capacity of people with ID to understand and assess their own health, express needs, and engage in research, either independently or with appropriate support (58, 59). However, newer studies about cancer prevention/screening include individuals with ID (64–66). The current results demonstrated that individuals with ID could participate in research, when supported by relatives and/or accommodations. This aligns with broader movements in Western healthcare systems toward co-production, shared decision-making, and user involvement in both care and knowledge production (67). Participatory research methods that actively involve people with ID can provide deeper insights into their experiences, promote equitable participation, and contribute to improvements in health policy and practice, including information practices (59, 68). However, this method requires resources, trust, and cultural change within research and clinical environments to overcome barriers and ensure that research and care become fair, inclusive, and effective (59, 69).

The current literature review has strengths and limitations. This review was carried out in accordance with the PRISMA 2020 guidelines, which ensure a systematic, transparent, and rigorous reporting of the review methods, thereby facilitating a clear evaluation of its quality (22, 70). Furthermore, the review protocol was pre-registered on PROSPERO, allowing public access to the original plan and enabling comparison with the completed manuscript. This pre-registration strengthens the transparency and credibility of the review process (71). Moreover, an experienced university librarian supported the systematic literature search process, which was supplemented by a final Google Scholar search, to ensure the retrieval of the most relevant and comprehensive studies aligned with the review's aim and research questions. This collaborative approach contributed to a rigorous and transparent search process. All articles that did not clearly distinguish between individuals with ID who have cancer and those without cancer were excluded. This approach ensures that the results specifically represent the group of individuals with concomitant ID and cancer. However, it also means that relevant information about this population involved in broader studies may have been missed in this review. Throughout the screening, data extraction, and analysis phases, the authors engaged in regular discussions and critical evaluations, thereby strengthening the reliability and credibility of the results. The quality of the included studies was appraised using the CASP qualitative checklist, with all studies rated as high quality, supporting the trustworthiness and relevance of the review findings. Nonetheless, the CASP tool has limitations, notably its omission of criteria assessing the studies' underlying theoretical, ontological, and epistemological frameworks, which are important aspects for a thorough quality evaluation (25). However, this literature review includes studies with low levels of evidence according to the evidence hierarchy (72), primarily due to their case study formats, which represents a limitation. Nevertheless, the current review encompasses all relevant studies identified and provides a valuable synthesis of an under-researched area within healthcare about individuals with ID facing cancer.

Conclusion

The current literature review revealed that individuals with ID responded to cancer and its challenges in diverse ways. Everyday routines often provided an important source of stability and functioned as a coping resource to preserve a sense of self and control when encountering uncertainty in living with cancer. Individuals with ID also showed an ability to live in the moment, which served as both a coping strategy and a source of strength throughout their cancer journey. Individuals with ID developed their understandings of cancer and their conditions through personal experiences such as seeing relatives having cancer or public figures. They received information about their diagnosis, treatment and prognosis to varying extents, influenced not only by differences in individuals with ID's capacities to understand and process information, but also by assumptions held by relatives and professionals about their (in)abilities to handle such information. These assumptions often resulted in limited information being provided to individuals with ID and cancer, which failed to respect their autonomy and rights to know. Future research must explore effective ways for relatives and professionals to communicate cancer information to individuals with ID that respects their autonomy and human rights to be informed and involved in decisions about their own cancer care. Future research should also focus on developing strategies for supporting person-centered routines within structured care systems that accommodate and empower individuals with ID to navigate cancer care trajectories.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

SG: Conceptualization, Formal analysis, Methodology, Project administration, Writing – original draft, Writing – review & editing. MC: Formal analysis, Writing – original draft, Writing – review & editing. MS: Writing – original draft, Writing – review & editing. CF: Formal analysis, Methodology, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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