Exploring barriers to mammography access for women with intellectual disabilities: a meta-synthesis of the perspectives of four stakeholder groups

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Keywords: intellectual disabilities, mammography, breast cancer, qualitative, inequalities, healthcare access

Abstract

Background: Breast cancer is as frequent in women with intellectual disabilities as the general population but the mammography uptake rate for women with intellectual disabilities is almost a third lower. This meta-synthesis aimed to explore physical and psychosocial barriers to mammography access for women with intellectual disabilities, from the perspectives of the women themselves, healthcare professionals, paid carers, and family members.

Method: A systematic search of six databases yielded twelve papers for thematic synthesis review.

Results: Three analytic themes were developed: (i) knowing what to expect; (ii) knowing who will assume responsibility; and (iii) making adjustments.

Conclusions: Mammography screening elicits anxiety from both women with intellectual disabilities, and their supporters (whether paid, family, or healthcare professional). A formulation-based approach to mammography attendance may help to provide tailored information to women with intellectual disabilities, whilst easing the pressures placed upon their support network and healthcare professionals.

Lay Summary

- Breast cancer screening can be worrying for women with intellectual disabilities and those that support them.
- Local services should seek to develop bespoke care pathways for the breast cancer screening of women with intellectual disabilities.
- Women with intellectual disabilities may benefit from an assessment that explores what they understand about breast cancer and breast cancer screening, what they would like to know, what are their breast cancer screening fears, and where are their learning strengths / challenges.

Introduction

Breast cancer is as frequent in women with intellectual disabilities as it is in women without intellectual disabilities (Patja et al., 2001). Regular breast cancer screening offers early detection, affords a greater treatment window, and can reduce breast cancer mortality by 15-28% (Weedon-Fekjaer et al., 2014; Nystrom et al., 2017). NHS statistics indicate that between 2016-2021, receipt of breast cancer screening for women with intellectual disabilities was 14.6% lower than that of persons without intellectual disabilities (NHS England Digital, 2021). The reduced breast cancer screening uptake for women with intellectual disabilities exists within a context of consistently reported inequalities in healthcare provision, and outcomes, that are experienced by people with intellectual disabilities (Disability Rights Commission, 2006; Michael & Richardson, 2008; Parliamentary and Health Service Ombudsman, 2009; Mencap, 2012; Francis, 2013; Emerson, 2021; Ramsey et al., 2022; White et al., 2023).

Reviews of primarily quantitative research have cited several barriers encountered by women with intellectual disabilities when accessing breast cancer screening. Willis et al. (2008) reviewed 35 articles to determine the broad state of knowledge on breast cancer for women with intellectual disabilities. Their paper included a summary of several barriers to breast cancer screening: method of referral; challenges with understanding invitations; transportation difficulties; physical disability / comorbid condition(s); and ill health of women with intellectual disabilities and/or their carer(s). Chan et al. (2022) reviewed 16 papers to integrate the factors influencing cancer screening among persons with intellectual disabilities. Barriers to cancer screening encompassed: fear of screening (including embarrassment); previous poor hospital treatment; attitudes of healthcare professionals (HCPs); poor knowledge among persons with intellectual disabilities regarding cancer screening; mobility difficulties and the logistics of the procedure; a high severity of intellectual disabilities; and difficulties with providing consent (Chan et al., 2022). Additional barriers include a lack of breast awareness promotion and/or knowledge among nursing (Kirby & Hegarty, 2010) and caring professionals (Hanna et al., 2011) that work with people with intellectual disabilities.

Qualitative and mixed-methods reviews have similarly highlighted challenges. Walsh et al (2022b) reviewed the literature on barriers to breast cancer awareness for women with intellectual disabilities, developing three themes: lack of their (women with intellectual disabilities) understanding; the role of the carer; and literacy issues. However, these themes were not supported with participant quotes from the reviewed articles, and the explicit focus on breast cancer awareness means that barriers to mammography itself were not fully considered. Byrnes et al. (2020) reviewed qualitative literature concerning the attitudes and perceptions of women with intellectual disabilities, family carers, and paid carers, towards cancer screening programmes in the UK. Four themes were reported: supporting women with intellectual disabilities to attend screening; awareness of screening and their psycho-physical experiences; professional practice barriers; and approaches to improve the uptake of cervical and breast cancer screening. Yet, by synthesising the experiences of both cervical and breast cancer screening together, it is possible that some of the nuance pertaining solely to the experience of mammography was lost.

The purpose of this article is to review qualitative research concerned with the experience of mammography screening for women with intellectual disabilities, from the perspective of four stakeholder groups: (i) women with intellectual disabilities; (ii) HCPs; (iii) paid carers; (iv) and family members. The review question is concerned with exploring the perceived physical and psychosocial barriers to mammography screening for women with intellectual disabilities.

Method

Identifying relevant literature

The PRISMA checklist of items to include when conducting a meta-synthesis (Moher et al., 2009) was referred to in the design and structure of the review. Search domains and associated search terms were developed using the SPIDER tool (Cooke et al., 2012) (see table 1). These terms were used to systematically search AMED, CINAHL complete, MEDLINE Complete, PsycINFO, SocINDEX and Web of Science databases in February 2024. Following consultation with a specialist librarian, free-text search terms were used, whilst MESH terms were not included. Text-word searching has been shown to have greater sensitivity when compared to searching via MESH terms (Jenuwine & Floyd., 2004), and this was felt to be advantageous given the limited qualitative research concerning women with intellectual disabilities and mammography screening. After the removal of duplicates, 187 papers remained. Titles and abstracts were screened using the following inclusion criteria: (i) available in English; (ii) published in a peer-reviewed journal; (iii) specified the use of qualitative data collection and analysis methods (variation among approaches was accepted, including mixed methods); (iv) reported on the experiences of at least one stakeholder group with regards to mammography screening for women with intellectual disabilities. Given that the review question concerns identification of a potentially life-threatening illness, the requirement for papers to be published in a peer-reviewed journal was felt important to ensure the selected papers had undergone a sufficient degree of scrutiny. Grey literature was not included in the search strategy as the majority is not peer-reviewed (Benzies et al., 2006). The remaining 18 papers were screened using the following exclusion criteria: (i) mixed methods were applied but findings were presented collectively, making the qualitative component unclear; (ii) qualitative methods were used, but the analysis was not supported by quotations/observations; (iii) the paper reported on several hospital and/or cancer experiences collectively, such that the specific experience of mammography was unclear; and (iv) the sample included various forms of disability and participants' experiences were reported together, such that the specific experience of women with intellectual disabilities was unclear. A total of 12 papers were included in the review (see figure 1 for visual depiction of search process).

Table 1. Free search terms utilised in systematic literature search strategy

SPIDER heading	**Search domain**	**Free-text search terms**
S – sample	People with intellectual disabilities	"learning disab*" or "intellectual disab*" or "intellectual development* disorder*" or "development* disab*" OR "mental* retard*" OR "mental* handicap*" OR "Down* syndrome" OR "Intellectual* impair*" OR "mental disab*" OR "prader willi" OR autism OR ASD OR asperg* OR "fragile X" OR "global develop* delay" OR rett OR angelman OR "fetal alcohol" OR "cerebral palsy" OR "turner syndrome"
PI – phenomena of interest	Mammography screening	"breast screen*" or "breast cancer screen*" or "breast cancer" or "breast neoplasm*" or "breast awareness" or "cancer awareness" or "cancer knowledge" or "breast knowledge" or mammography or "national screening programme" or "breast cancer detection" or "cancer detection" OR "cancer screen*" OR "breast exam*" OR "breast self exam*"
D – design	Qualitative research	qualitative* OR interview* OR "focus group*" OR Phenomeno* OR IPA OR "interpretative phenomenological" OR "case stud*" OR observ* OR "grounded theory" OR narrative OR thematic OR theme OR themes OR experienc* OR "content analysis" OR ethnolog* OR "conversation analysis" OR views OR attitude* OR Percept*

*The authors recognise that some of the free-text search terms are pejorative and do not reflect their views. The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. These terms have been included to permit the widest possible scope for the literature search.

Quality appraisal

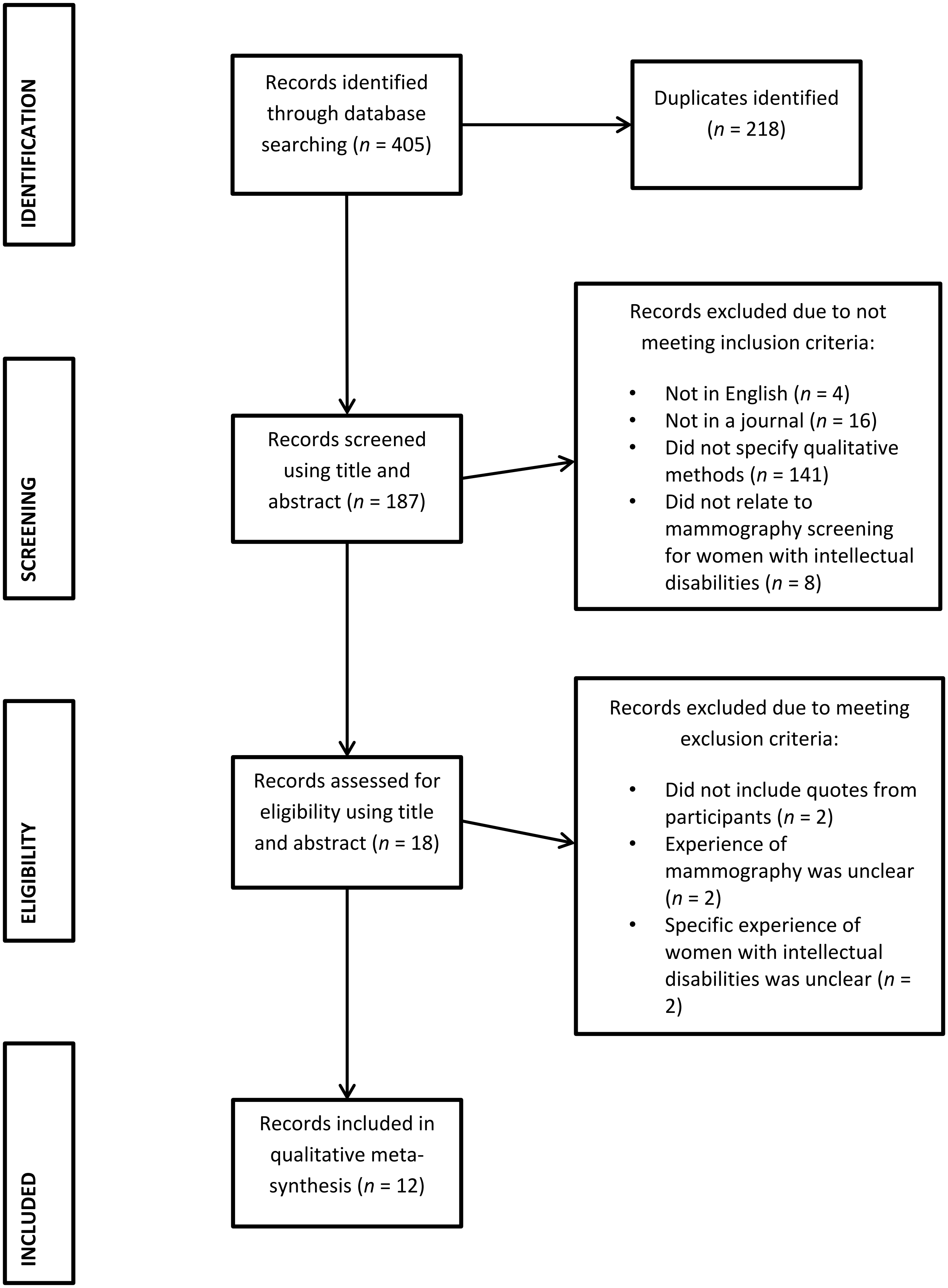
Although utilising a checklist to appraise the quality of qualitative papers is subject to ongoing debate (Walsh et al., 2015), as a matter of methodological transparency, a checklist was applied. Papers were appraised for their quality and validity using an adapted version (Lord et al., 2017) of the 10-point Critical Appraisal Skills Programme checklist for qualitative research (Critical Appraisal Skills Programme [CASP], 2013). The adapted version allows researchers to assign a grade of weak, moderate, or strong in relation to the questions posed by the CASP tool, resulting in a final quality score ranging from 8 (representing the lowest possible score) to 24 (the highest possible score) (see table 2 for completed CASP scores). Quantitative quality scores afford readers the opportunity to make crude comparisons between the papers. The mean CASP score was 15.33 (range = 12 – 18). The question with the lowest scores pertained to consideration of the relationship between the authors and the participants (CASP question 6). For example, authors rarely examined their own role, potential bias, and influence during the development and conduct of the research. Although numerous authors described their data analysis as "informed by" a particular strategy (e.g. grounded theory), there was no explicit description of how this was achieved. Therefore, it was difficult to ascertain whether some of the papers had conducted a sufficiently rigorous data analysis (CASP question 8).

Table 2. Quality appraisal of studies included in the qualitative meta-synthesis

CASP checklist item	**Study number**											
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Was there a clear statement of the aims of the research? (Y/N)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate? (Y/N)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research? (1-3)	3	3	2	3	1	1	1	2	2	3	1	2
Was the recruitment strategy appropriate to the aims of the research? (1-3)	2	2	2	3	3	2	2	2	2	2	3	2
Was the data collected in a way that addressed the research issue? (1-3)	2	2	3	2	2	2	2	2	2	2	2	2
Has the relationship between researcher and participants been adequately considered? (1-3)	2	1	1	1	1	1	1	2	1	2	1	2
Have ethical issues been taken into consideration? (1-3)	3	2	3	3	2	2	1	2	3	2	1	2
Was the data analysis sufficiently rigorous? (1-3)	2	2	2	2	2	1	1	2	1	2	2	2
Is there a clear statement of findings? (1-3)	1	1	1	2	2	2	2	2	2	2	2	2
How valuable is the research? (1-3)	2	1	2	2	2	2	2	3	2	2	2	2
Total CASP score (out of 24)	17	14	16	18	15	13	12	17	15	17	14	16

*Papers rated for each CASP item as either weak (1), moderate (2), or strong (3).

Figure 1. Flow diagram depicting systematic literature search strategy



Methodology

The purpose of a qualitative meta-synthesis is to analyse and synthesise meaning across a collection of research around a given experience, and to interpret these meanings by developing new explanatory concepts (Polit & Beck, 2006). The thematic synthesis approach of Thomas and Harden (2008**)** was used throughout this paper. Thematic synthesis is well-matched to the present research question as the method was specifically developed to conduct qualitative reviews pertaining to intervention need, appropriateness and effectiveness (Barnett-Page & Thomas, 2009).

Thematic Synthesis

"Data" was taken to mean all text within the results and/or findings sections of the identified papers. All studies were coded (inductively) line-by-line. Codes from each paper were entered into a grid and analysed separately to arrive at a catalogue of paper-specific concepts (Walsh & Downe, 2005). These concepts were then grouped together and analysed for similarities and differences to develop a set of descriptive themes across papers. Descriptive themes were analysed and interpreted in the context of the review questions, resulting in new meanings and the development of more abstract analytic themes.

Characteristics of selected studies

Table 3 displays the key characteristics for each of the papers included in the meta-synthesis. The 12 papers were published between 2004 and 2022; six of which were conducted in the UK, three in the USA, one in Australia, one in the Republic of Ireland, and one which did not state where the study was conducted. The extent to which demographic information was reported for the various participant groups varied across the included papers. There were 252 participants in total across all 12 papers – 11 of those papers provided figures on the number of participants specifically recruited from each stakeholder group. Totalling across those 11 papers, 66 participants were women with intellectual disabilities, 43 were HCPs, 59 were paid carers and 59 were family carers. Two papers utilised the same sample of 27 women with intellectual disabilities (included once in the calculation of the total number of participants across all papers, and the total number of women with intellectual disabilities who participated); however, each paper posed different research questions.

The papers reported here employed a variety of qualitative methods, including interviews (eight papers), focus groups (six papers) and observational techniques (two papers). All 12 papers utilised qualitative coding techniques to analyse their data. Specific analytic techniques included variations on thematic approaches, content analysis, coding informed by grounded theory, and coding informed by interpretative phenomenological analysis.

Table 3. Key characteristics of reviewed studies, in order of year of publication

Study Number	Author (year)	Research aim(s)	Sample description	Data collection strategy	Method of data analysis	Country
1	Sullivan et al. (2004)	Explore barriers and enablers for mammography screening among women with intellectual disabilities and to determine the interplay between these factors	30 direct care workers employed within hostels	Four open-ended focus groups	Unspecified thematic analysis	Australia
2	McIlfatrick et al. (2011)	Ascertain the perspectives of HCPs on their role in supporting women with intellectual disabilities to access mammography screening	9 Primary care staff and 9 hospital breast cancer screening staff	14 semi-structured interviews and 1 semi-structured focus group	Thematic content analysis	Northern Ireland
3	Taggart et al. (2011)	Examine how CIDN [1]and RCS [2] support women with intellectual disabilities to access breast cancer screening	16 CIDN and 13 RCS	Six semi-structured focus groups	Thematic content analysis	Northern Ireland
4	Truesdale-Kennedy et al. (2011)	Describe the understanding of breast cancer, and experiences of breast mammography, among women with intellectual disabilities	19 women with intellectual disabilities residing in a residential setting	Four semi-structured focus groups	Thematic content analysis	Northern Ireland
5	Wilkinson et al. (2011)	Understand decisions about mammography from the perspective of women with intellectual disabilities and to explore aspects of their knowledge, experiences, and expectations leading to a decision to have / not have a mammography.	27 women with intellectual disabilities	Semi-structured interviews	Thematic analysis informed by grounded theory	USA

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[1] Community intellectual disabilities nurses

[2] Residential care staff

6	Swaine et al. (2013)	Explore family members' perspectives on breast and cervical cancer screening for women with intellectual disabilities, including their thoughts on possible health inequalities, and any facilitators to cancer screening	32 family caregivers	Semi-structured interviews	Qualitative coding	USA
7	Collins et al. (2014)	Determine what is known about the needs of people with intellectual disabilities to promote early awareness and earlier presentation of breast cancer symptoms and ensure optimal breast cancer treatment and management	25 "key stakeholders" including those from national statutory and voluntary bodies, managers and practitioners from local organisations, and three women with intellectual disabilities	25 interviews, and one focus group featuring three women with intellectual disabilities	A thematic "framework approach"	England
8	Greenwood et al. (2014)	Explore family members' attitudes toward preventive health care and decision making for their relative with intellectual disabilities, their perspectives regarding what constituted high-quality health care for their relative, and their ideas regarding barriers and facilitators of mammography screening	16 family members	Semi-structured interviews	Content analysis and grounded coded theory	Not stated

9	Willis et al. (2015)	Explore the views and experiences of paid and family carers when supporting women with intellectual disabilities through breast cancer screening	10 paid carers and three family carers	13 semi-structured interviews, and two structured observations of discussions around breast health	Thematic analysis	Scotland
10	Willis (2016)	Understand what influenced women with intellectual disabilities to participate in mammography screening and to explore their experience of having a mammography	12 women with intellectual disabilities	12 semi-structured interviews, and three observations of discussions around breast cancer screening or observed attendance at a mammography	A “blended framework”, informed by interpretative phenomenological analysis	Scotland
11	Arana-Chicas et al. (2020)	Explore mammogram barriers and facilitators among women with different severities of intellectual disabilities	18 women with intellectual disabilities, eight family caregivers, and four residential staff caregivers	Qualitative interviews following a bespoke instrument developed for the study	Thematic analysis	USA
12	Walsh et al. (2022a)	Determine the views of participants as to whether there is a need for a breast cancer awareness educational intervention for women with intellectual disabilities, and to provide perspectives on the preferred processes and content underpinning such an intervention	14 women with intellectual disabilities living in the community, two caregivers, and nine HCPs	Five individual semi-structured interviews and five separate focus groups, using similar questions	Qualitative content analysis	Republic of Ireland

Table 4. Thematic grid charting the development from descriptive to analytical themes

Concepts / Codes	**Descriptive Themes**	**Analytical Themes**
Sources of information: past-experience; media; charities; caregivers; HCPs / services	Understanding of breast cancer and mammography is multifaceted and comprised of varied data sources	Knowing What to Expect: distress experienced by women with intellectual disabilities is, in part, a response to the level of understanding which they have concerning breast cancer and mammograph
Types of information: risk; prevention; identification		
Affective Presentation: temperament; embarrassment; fear; pain; resilience; cognition; distress	Breast cancer and mammography elicit distress from women with intellectual disabilities	
Standard Protocols & Materials: logistical issues; lack of training; absence of guidelines;	Implementing standard practice poses challenges when working with women with intellectual disabilities	Knowing who will assume responsibility: women with intellectual disabilities are keen to be involved in their breast-health, but their needs are not always compatible with standard practice. Supporting stakeholders perceived that on those occasions where a woman with intellectual disabilities cannot consent to treatment, others would need to assume responsibility for facilitating breast cancer screening. There was uncertainty regarding whom should assume / share that responsibility.
Personnel & Rapport: HCP experience; attitude of HCP; communication skills; gender of HCP		
Capacity and consenting to treatment: severity of intellectual disabilities; communication skills; unclear roles; making the right decision	Supporting stakeholders perceived that *some* women with intellectual disabilities may lack capacity to consent to treatment, which can lead supporters to worry about making decisions on the behalf of some women with intellectual disabilities.	
Assistive use of Caregivers: present at appointments; facilitating communication; flagging the presence of intellectual disabilities; advocating rights; monitoring health	Caregivers may adopt assistive and/or substitutive positions in the process of performing a multitude of tasks that would facilitate breast cancer health and mammography access	Making adjustments: women with intellectual disabilities may receive additional support, whether from family caregivers, paid caregivers, or HCPs. Adjustments could be categorised as either assistive, persuasive, or substitutive.
Substitutive use of Caregivers: deferring to carers for communication; influencing decision making; persuading; making decisions for others; capacity		

Results

Three analytical themes were developed: (i) knowing what to expect, (ii) knowing who will assume responsibility, and (iii) making adjustments. Table 4 shows a thematic grid representing how the analytical themes were derived from the descriptive ones. All four stakeholder groups contributed to each of the analytical themes.

Knowing what to expect

All the papers presented mammography as a procedure that elicits varying degrees of distress from women with intellectual disabilities, whether this be in anticipation of, during, or after the procedure. Women with intellectual disabilities discussed feeling "embarrassment" (S4, p.1299; S10, p.273) / "embarrassed" (S5, p.146; S11, p.8,), "scared" (S4, p.1299; S10, p.273; S11, p.25), and "afraid" (S4, p.1299; S12, p.5), whilst the procedure itself was described as "painful" (S4, p.1299; S10, p.273; S11, p.6). The three remaining stakeholder groups echoed these views, with each one commenting that women with intellectual disabilities would likely experience "fear" and "pain" (S3, p. 47; S8, p.449; S9, p. 477) as a response to mammography screening.

For many of the women with intellectual disabilities, their emotional response appeared to be linked to their knowledge of breast cancer/mammography. Several authors described the breast cancer knowledge of women with intellectual disabilities as "limited" (S1, p.400; S3, p.46; S4, p.1298; S12, p.7). Those women with intellectual disabilities that spoke of breast cancer did so in basic terms, e.g. "It's like a germ in your blood" (S4, p. 1298). Many women with intellectual disabilities that attended a mammogram talked of not knowing what the procedure would entail, suggesting their distress may be likened to a fear of the unexpected. One woman with intellectual disabilities suggested that supporting patient understanding may lead to a better experience, “Many people with intellectual disabilities…don’t really understand what a mammogram is about, and if it was explained to them and explained that it’s gonna hurt but this is what it’s for…maybe it wouldn’t be so hard on them.” (S5, p. 145).

HCPs intimated that attendance/compliance with a mammogram was primarily an issue of a lack of understanding on the part of women with intellectual disabilities, “The women don’t want to go to screening because they don’t understand” (nurse, S7, p. 894). Family members and paid carers appeared to agree that a greater understanding of what to expect would be associated with a smoother mammography; with one family member commenting: “It helped to talk [my daughter] through it…what they are going to do” (S6, p. 66). One author noted that adult day programs represent a good opportunity for peers to share knowledge, as illustrated by one woman with intellectual disabilities, “I talk to my friends about going to the doctor.” (S11, p. 9). Women with intellectual disabilities may also learn about breast cancer/mammography via the media, “I watch it in the commercials about breast cancer, so I always look at the commercials. I know people are dying from that.” (woman with intellectual disabilities, S11, p. 10).

Both paid carers and family members perceived that the severity of a person’s intellectual disabilities would be linked to more profound cognitive deficits, which would limit what could be learned. A paid carer who worked with people with severe/profound intellectual disabilities discussed the meaning of the word, *cancer*, to those they support, “Whether cancer means anything is debatable because cancer the word can instil a huge amount of fear but I can honestly say with a whole lot of our service users it would mean absolutely nothing, it could be broccoli.” (S9, p. 477). One author quoted a consensus among HCPs that caregivers had “poor” (S12, p. 6) levels of breast cancer awareness. A family member in the same study stated they did not “know how you’d actually go about” educating their daughter (S12, p. 5). Thus, knowing what to expect is dependent, in part, on paid carers and family members possessing both knowledge of breast cancer/mammography, and *how* to deliver that knowledge effectively to women with intellectual disabilities.

Knowing who will assume responsibility:

All stakeholder groups acknowledged that the needs of women with intellectual disabilities are not always compatible with *standard* breast cancer screening practice. Challenges included cognitive and communicative deficits ("He [doctor] tries to explain a procedure but I just couldn't understand" (woman with intellectual disabilities, S11, p. 25)); existing health concerns ("Her right side is paralyzed" (family carer, S11, p. 10); "existing severe medical problems" (paid carer, S1, p. 401)); and logistical concerns, including appointment length, transportation and finance issues ("So a transport practicality may prevent them from coming." (breast care nurse, S2, p. 416)).

Women with intellectual disabilities were keen to be involved in their breast-health, "…what's the best signs for me to help me, to encourage me to check myself more often for preventing cancer in the future" (S12, p. 6). Similar to *knowing what to expect*, the three remaining stakeholder groups anticipated that intellectual disabilities would limit the extent to which women with intellectual disabilities could assume responsibility for their healthcare, "Examination may be a problem whether that be because perhaps they would be unable to do it or they wouldn't understand the importance of it or what they would be looking for" (breast cancer nurse, S2, p. 415). The supporting stakeholder groups expected that, at times, others may need to assume responsibility for facilitating breast cancer screening. However, there was a lack of clarity over *who* should assume such responsibility.

Several HCPs believed paid carers and family members should support women with intellectual disabilities to undertake initial checks, "…for [people with intellectual disabilities] we need awareness for them and for carers/family and clear guidelines about how to self-examine and what to look for." (GP, S7, p. 894). Of note, the GP does not suggest anyone for this educational role, contributing further to the uncertainty regarding the roles and responsibilities of supporters. Numerous paid carers questioned whether it is appropriate for them to undertake breast checks at all, owing to *their* vulnerability, "…we had explained that it was inappropriate for us and really we couldn't...there is a lot of issues in relation to staff, you know, accusations that can be made against staff" (S3, p. 48). Paid carers spoke of conducting simple and discrete checks as part of approved personal hygiene support, "When you are drying you are aware of anything very obvious or a change or if there was a lump" (S9, p. 476). The wording, *very obvious*, underscores that this paid carer believes there is a limit on the quality of check they can undertake and, when paired with concerns about staff vulnerability, the indication is that HCPs should assume responsibility for a *thorough* exam. Similarly, family members felt it was the responsibility of healthcare services to improve mammograms so that they worked better for women with intellectual disabilities, "A mammogram should have special machines for them so they can do the same thing as everyone else." (Family caregiver, S11, p. 26).

Assuming responsibility for consent to treatment provoked anxiety among the supporting stakeholders. First, supporters feared that ***someone else*** might make a decision that was not in the best interest of women with intellectual disabilities. HCPs questioned whether family members view screening as "a priority" or "appropriate" (nurse, S3, p. 47), and there was evidence that such perspectives may be true for some, “I think I just thought because [my daughter] had a hysterectomy she just doesn't need to go in.” (mother, S6, p. 66). Thus, a knowledge deficit among family members may lead to reduced mammogram attendance. Whilst paid carers acknowledged variability among the decisions of family members, they made the same assumption of HCPs, noting how one GP advised against breast cancer screening based on the client’s severity of intellectual disabilities, “he just said it would not be a good idea” (paid carer, S9, p. 478). Second, supporters feared that ***they*** could make a decision that was not in the best interest of women with intellectual disabilities, “It’s hard to be making decisions for someone who can’t tell you what they would want” (family member, S8, p. 447). The weight of responsibility to make the right decision was also noted by HCPs, “So then, if something does happen to their person subsequently, then that is even more devastating then as somebody else has taken on the surgical planning” (S12, p. 6). Whereas family carers were fearful of their responsibility to represent their loved one accurately, HCPs were fearful of their responsibility to ensure procedures went as planned.

Linking the fears regarding responsibility for consent is that the decision would be made by a ***single person***. By contrast, one paid carer stated they would seek the support of others, “We would involve the Community [Intellectual] Disability Team, and see whether we should do this and seek more information about this issue” (S9, p. 477). This extract implies that the responsibility for making decisions in someone’s best interests should be shared among a team of people.

Making adjustments

Despite an absence of clarity regarding who should assume responsibility for facilitating breast healthcare, all stakeholder groups shared examples of having either provided, or witnessed, additional support for women with intellectual disabilities. Examples included support from family caregivers, paid caregivers, and HCPs. Adjustments could be categorised as either assistive, persuasive, or substitutive.

Assistive adjustments empowered women with intellectual disabilities to consent to, and attend, breast checks / mammograms. Assistive adjustments included emotional, communicative, or practical support for women with intellectual disabilities. Family / Paid caregivers were frequently acknowledged as providing “moral support” (woman with intellectual disabilities, S10, p. 44). HCPs were also recognised for emotional support; however, this was said to be less common, “She [mammogram technician] helped me relax. For so many it’s not so important to take the time to help you relax.” (woman with intellectual disabilities, S11, p. 7). Including paid / family caregivers at appointments was viewed by some as crucial to assisting with communication, “I don’t think they [woman with intellectual disabilities] would have ever gone through with any of the screening unless that they had the support of someone to communicate on their level.” (HCP, S2, p. 416). The implication is that the HCP was fearful of their own ability to communicate with women with intellectual disabilities, independent of support from caregivers. Whilst the communication skills of HCPs were frequently questioned by the remaining three stakeholder groups (“People don’t know how to approach our guys – they look at us as if to say ‘Help!’” (paid carer, S1, p. 402)), some positive interactions were identified, “Yeah [my doctor] talks to me. She doesn’t ignore me. She ain’t that type of doctor.” (woman with intellectual disabilities, S11, p. 8). The statement, *She ain't that type of doctor*, suggests that positive communication with HCPs is no certainty.

Practical assistance was also recognised, such as family and paid caregivers sharing information with HCPs ("I mentioned that she had a developmental delay and that might be why she wasn't cooperating." (paid carer, S1, p. 402); scheduling appointments ("I keep all her appointments…" (family caregiver, S11, p. 7)); requesting a "double appointment" (author, S9, p. 478) to afford extra time, and making adaptations to the procedure, such as offering anaesthetic, or an ultrasound as an alternative to mammography ("For the ultrasound we lay her on her own bed. We turn down the lights and make it a little bit more calming environment" (Paid caregiver, S11, p. 10).

Persuasive adjustments involve altering information provided to women with intellectual disabilities to *encourage* their consent to breast cancer screening. Persuasive techniques abandon impartial assistive communication adjustments and, instead, present a *biased* version of information, "…saying I go for it and we all go for it once we get to a certain age and it is sort of for the good of your own health." (paid carer, S9, p. 477). The biased statement, *we all go for it*, does not acknowledge that some people decline mammograms, regardless of whether they have intellectual disabilities. Paid carers spoke of fulfilling their "duty of care" (S1, p. 401) towards women with intellectual disabilities and, within that context, persuasive language may be viewed as a demonstration of preserving life. Accounts from women with intellectual disabilities indicate that HCPs may also use persuasive language to encourage consent and preserve life, "Yes [my doctor] talks to me about mammograms. I have to do it." (woman with intellectual disabilities, S11, p. 8). The wording, *have to do it*, suggests the individual believed themselves to have no choice. These quotes illustrate the fine line between well-intentioned attempts to normalise and demystify mammograms, and biasing information such that informed consent may be impeded.

Substitutive adjustments involved removing the power to consent from women with intellectual disabilities altogether and substituting someone else in their place. Most often, removing the power to consent was evidenced by family caregivers choosing to withhold information from their loved one, "…you know you're always thinking about well what if it shows something, then what would we do, and I haven't acted on it." (mother, S8, p. 448). This mother indicates that discussions around mammography are closely linked to the results of the procedure, provoking fears associated with the uncertainty that can accompany a cancer diagnosis. Family carers indicated that breast cancer treatment "…might be too traumatic for her [their loved one]" (family carer, S8, p. 448), leading some family carers to conclude that when deciding whether to pursue breast cancer treatment, they would not be "…as aggressive as we would be if it was me, or my husband." (S8, p. 448). These quotes mirror reports from HCPs that they have known some family caregivers to choose not to inform their loved one about breast cancer screening invitations because, "it was a taboo subject that they (family carers) did not want their loved ones (woman with intellectual disabilities) to be aware of" (CIDN, S3, p. 47). Although these actions are understandable from the perspectives of caring family members that want to protect those they love from the harsh realities of a life-threatening illness; delaying a mammography or declining treatments places women with intellectual disabilities at greater risk of cancer-related death.

Discussion

This meta-synthesis aimed to explore the perceived physical and psychosocial barriers to mammography access for women with intellectual disabilities; from the perspectives of the women themselves, HCPs, paid carers, and family members. Findings indicated that breast healthcare for women with intellectual disabilities elicits anxiety from all stakeholders. Mammography-related distress was a common barrier among women with intellectual disabilities, and can be interpreted, in part, as a response to limited knowledge of both breast cancer and mammography. Whilst women with intellectual disabilities expressed a desire to be educated and/or involved in their breast healthcare, the three supporting stakeholder groups anticipated that intellectual disabilities would limit the extent to which women with intellectual disabilities could assume responsibility for their own healthcare. However, there was little consensus among those stakeholders as to *whom* should assume that responsibility, and an acknowledgement that best interests' decisions elicit anxiety from decision-makers. Supporting stakeholders were concerned that either they, or someone else, might make a decision that was not in the best interest of women with intellectual disabilities. All stakeholder groups shared examples of having either provided, or witnessed, additional support for women with intellectual disabilities in the form of assistive, persuasive, or substitutive reasonable adjustments. Whilst assistive adjustments empowered women with intellectual disabilities to consent to / attend healthcare appointments; persuasive and substitutive adjustments posed barriers to consent by either fundamentally altering information or withholding information altogether. Persuasive and substitutive adjustments raise ethical concerns around impeding women with intellectual disabilities from providing truly informed consent and achieving the level of healthcare involvement that they desire.

All stakeholder groups acknowledged that the needs of women with intellectual disabilities can present barriers to *standard* breast cancer screening. Barriers included cognitive and communicative deficits, coexisting healthcare concerns / disabilities, transportation / finance issues, and practical issues with the appointment itself (e.g., longer appointment times, incompatible equipment etc.) These findings are consistent with barriers reported elsewhere in the intellectual disabilities' literature concerning access to both general healthcare (Doherty et al., 2020; Shady et al., 2022), and mental healthcare (Whittle, et al., 2018).

Each stakeholder group identified that many women with intellectual disabilities experience mammography-related psychological and physical distress, both in anticipation of, and during the procedure – consistent with earlier quantitative research (Willis et al., 2008). Although women *without* intellectual disabilities also report anticipatory fear with regards to cancer screening (Consedine et al., 2004), one review described their distress levels as low, concluding that it is unlikely that their distress would act as a widespread barrier to cancer screening (Chad-Friedman et al., 2017). Self-efficacy may be key, with it reported to play a facilitative role in increasing the likelihood of mammography attendance among women, generally (Purtzer & Overstreet, 2014). Representatives from all stakeholder groups expressed that the fears of women with intellectual disabilities could be allayed and/or mammography attendance improved if women with intellectual disabilities had a greater awareness of what to expect from the procedure. It is possible that knowing what to expect increases self-efficacy among women with intellectual disabilities.

Best practice guidelines assert that women with intellectual disabilities should be supported to understand both what breast cancer is, and what screening entails **(**NICE, 2018a**)**, with the goal of supporting all women to make informed decisions regarding mammography attendance (NICE, 2017a). Yet, there was confusion among the supporting stakeholders as to each others' roles. Though HCPs noted paid and family caregivers are both well placed to undertake initial checks and possess skill in adapting information, there was a consensus among all supporting stakeholders that the breast cancer knowledge of both paid and family caregivers was poor. A review of effective teaching described good subject knowledge as an essential perquisite for educators (Ko & Sammons, 2013). For HCPs the inverse was said to be true. Their breast cancer knowledge was presumed to be high, but their ability to adapt communication / standard practice into an experience that is accessible to women with intellectual disabilities was said to be poor. The finding that HCPs struggle to adapt their communication skills is consistent with contemporary research on barriers to healthcare access for persons with intellectual disabilities (Shady et al., 2024)**.**

Supporting stakeholders felt that for some women with intellectual disabilities, satisfactory health-education would be difficult to achieve owing to cognitive and communicative challenges linked to the *severity* of their intellectual disabilities. Sullivan et al. (2003) report that cognitive deficits create difficulties in terms of understanding the mammography procedure, contributing to anxiety for women with intellectual disabilities. These cognitive and communicative challenges were cited by the supporting stakeholders as the primary reasons why women with intellectual disabilities would be unable to consent to their breast cancer screening. This is consistent with the wider intellectual disabilities literature that capacity to consent to healthcare decisions is deemed greater for persons with higher cognitive and verbal skills (Goldsmith et al., 2008). Nevertheless, the Mental Capacity Act (2005) specifies that the ability to consent to a given decision should be assumed until evidence to the contrary. The response of the supporting stakeholders in this meta-synthesis indicates that the presence of intellectual disabilities may be viewed by some as reason alone to doubt a person's ability to consent to treatment.

Whilst capacity to consent to healthcare decisions may be somewhat influenced by cognitive abilities, the results of this meta-synthesis show that women with intellectual disabilities are not consistently being presented with accessible information from which they can make an informed decision. The findings that the breast cancer knowledge of paid and family caregivers was said to be poor, and that HCPs struggle to adapt their communication, imply that the *quality* of the educational information provided to women with intellectual disabilities may be poor and/or inaccessible. Family carers were also noted to substitute themselves into the decision-making process by withholding information from their loved one, echoing reports of paternal attitudes towards decision-making for adults with intellectual disabilities (Bigby et al., 2019). Family caregivers' decisions were underpinned by issues with breast cancer knowledge, as well as fears of mortality, and physical pain, that are associated with mammography. Grounded in an earnest desire to fulfil their duty of care and preserve life, both paid caregivers and HCPs evidenced a tendency towards persuasive language when describing both mammography and breast cancer. Similarly, Dunn et al. (2024) reported that HCPs may coerce persons with intellectual disabilities into a choice. The use of persuasion presupposes that women with intellectual disabilities are likely to decline a mammography, and that such a decision would *be wrong* – a view which is likely informed by the high incidence of anticipatory distress reported in this meta-synthesis.

The supporting stakeholders acknowledged the weight of responsibility, and anxiety, which comes with making decisions in the best interests of others. Supporting stakeholders were concerned that either they, or someone else, might make a decision that was not in the best interest of women with intellectual disabilities. These two outcomes imply that supporting stakeholders may perceive a single person to possess responsibility for decisions concerning consent to treatment for women with intellectual disabilities.

Recommendations

The lack of clarity experienced by supporters regarding the tasks/responsibilities that they/others must undertake suggests that, in its current form, the national breast cancer screening pathway in England (Office for Health Improvement & Disparities, 2021) does not engender confidence. Local services should look to develop a bespoke intellectual disabilities breast cancer screening care pathway, which recognises both evidence-based approaches and local needs and resources, so that minimum standards of delivery can be established (Royal College of Psychiatrists, 2014). Ideally, their development should also include consultation with women with intellectual disabilities, professionals, families, and carers (Royal College of Psychiatrists, 2014). Weise and colleagues (2024) have advocated for further research to aid development of an accessibility audit tool to improve access to breast cancer screening for women with intellectual disabilities. Such a tool may help with guiding and monitoring bespoke breast cancer screening care pathways. Whilst new ways of working can themselves prompt anxiety, care pathways in intellectual disabilities services are valued by HCPs and viewed as benefiting patients via improved coordination and standardisation of care delivery (Wood et al., 2014). Alongside existing literature, the following recommendations could be used to guide care pathway development.

The findings of this meta-synthesis support existing healthcare recommendations that persons with intellectual disabilities would benefit from: extended appointments; use of visual supports / accessible information; attendance alongside a family and/or paid caregiver for both emotional and communicative support; and consideration of adaptations to the screening process/equipment/environment (Bradbury-Jones et al., 2013; Doherty et al., 2020; Ramsey et al., 2022). Family and paid caregivers may also benefit from basic breast healthcare training to support women with intellectual disabilities to understand what breast cancer is, to detect potential signs of breast cancer, and how to seek appropriate support. Ideally, the training should acknowledge the emotional impact that breast cancer conversations can have on families, and whom caregivers can approach for *their own* support needs. Women with intellectual disabilities spoke glowingly of HCPs that offered them time, addressed them directly, provided reassurance, and altered their communication, but this was said to be the exception to the rule. Consequently, the authors concur with others (Chan et al., 2022; Weise et al., 2024) that HCPs would benefit from training on how to adapt their communication for persons with intellectual disabilities.

With regards capacity to give informed consent to treatment, the authors support the view of Dunn et al. (2024) that training is essential for HCPs otherwise services risk perpetuating traumatic healthcare experiences and reducing trust. Paid caregivers, family members, and women with intellectual disabilities may all benefit from bespoke resources detailing informed consent to treatment and basic rights. Though developed for consenting to research, Taua et al. (2014) suggest 20-points to consider when gathering consent from persons with intellectual disabilities and these could provide a good spine for developing consent resources. Supporters must understand that capacity should first be assumed, nor should capacity to consent to treatment be questioned solely due to the severity of a disability (Mental Capacity Act, 2005).

Resources should include the legal duty upon services/supporters to reasonably adjust practices – not only regarding consent, but generally – so persons with intellectual disabilities are not disadvantaged (Equality Act, 2010). Supporters must recognise that all persons have a legal right to make decisions that others might consider unwise (Mental Capacity Act, 2005). Indeed, as of 2023, uptake of NHS breast cancer screening invitations for women in England was 62.3% (NHS England Digital, 2024), suggesting that non-attendance is not uncommon. Capacity, consent, and best interests' decisions should be considered a multidisciplinary endeavour that draws on the respective strengths of supporters whilst dispersing the responsibility among all parties. Guidance suggests including the decision-maker and a family / paid carer, as a minimum (NICE, 2018b; British Medical Association, 2019). Given the weight of responsibility, and anxiety, that supporters reported with regards making decisions in the best interests of others, it is essential that an MDT approach to consent is formally standardised within any intellectual disabilities-specific breast cancer screening pathway. Indeed, a recent Delphi study concerning strategies for accessible breast cancer screening for persons with intellectual disabilities recommended that services develop clear guidelines regarding consent (Weise et al., 2024). To support the MDT, Bigby et al. (2019) suggest decision-making resources should also include strategies that foster collaboration and guidelines for resolution of conflict.

Though it has been acknowledged that patients, carers and families may experience psychological distress following a cancer diagnosis (MacMillan Cancer Support, n.d.), this meta-synthesis highlights that many women with intellectual disabilities, and their family members, experience psychological distress *prior to* a mammogram. The authors agree with Byrnes et al. (2020) that psychosocial support is needed to alleviate breast cancer screening distress. Prior to their screening, women with intellectual disabilities may benefit from a formulation-based approach. This could explore what the person understands about breast cancer and the screening process (including the potential outcomes, e.g., all clear, cancer diagnosis, inconclusive results, false positives, and overdiagnosis), what they would like to know, what are their fears, and where are their learning strengths / challenges. Involving paid carers and family members in this process – with consent – may help to alleviate some of their distress associated with whether / how to broach the topic of cancer. The assessment should be conducted by a professional with experience of working with people with intellectual disabilities in a mental health capacity (NICE, 2017b), to help ensure that issues of autonomy, capacity, and reasonable adjustments are held in mind – e.g., in England, such formulations may be headed by community intellectual disabilities teams. The formulation could be used to inform what information is shared with women with intellectual disabilities, and how best to share it. With consent, an easy-read paper copy of the formulation could be generated and shared, like the established *Hospital Passport* and *All About Me* initiatives in England which are designed to succinctly communicate crucial information pertaining to individuals with specific support needs.

Strengths and Limitations

To the authors' knowledge, this is the first qualitative systematic review that has explored mammography access for women with intellectual disabilities from the perspective of four stakeholder groups. Gathering the views of each stakeholder group has allowed for comparisons and contrasts between groups, rather than observing their experiences as removed from each other. Nevertheless, caution should be taken when comparing the views expressed by stakeholder groups. Communication difficulties are not uncommon for persons with intellectual disabilities.

In their population sample of 601 adults with intellectual disabilities, Smith et al. (2020) found 57.9% experienced communication difficulties, with 23.5% experiencing severe difficulties. Due to their ability to take part in an oral interview study, the views of the women with intellectual disabilities presented in this meta-synthesis may not be reflective of those women who experience severe communicative difficulties. It is plausible that the views of women with intellectual disabilities who experience severe communicative difficulties were obtained by proxy through the reports of the family and paid carers that support them. Therefore, the family and paid carers that were interviewed may be reporting on experiences of supporting women with intellectual disabilities that differed markedly from the women with intellectual disabilities that were interviewed. Though inherent to the nature of a thematic synthesis, caution should be exercised as the present authors are not privy to the source data for each reviewed article. Rather, the authors are offering an interpretation on the data presented in the reviewed articles (which themselves reflect an interpretation of *their* authors). Whilst the focus of the meta-synthesis was to explore physical and psychosocial barriers to mammography access for women with intellectual disabilities, as a clinical psychologist within a community intellectual disabilities team, the lead author was aware of a bias towards recognising the *emotional toll* of the mammography experience. To aid transparency, the present authors have clearly detailed the methods employed, have triangulated data, and have supported their analysis with several direct quotes (spanning all 12 reviewed papers).

The systematic search resulted in 12 papers – a relatively small number for a meta-synthesis – whilst CASP scores indicated low-to-average quality among them. The low number of papers identified by the systematic search, and the CASP scores associated with those papers, signifies a need for a greater volume of high-quality qualitative explorations of mammography access for women with intellectual disabilities. Combining text-word searches alongside a search of MESH terms may have increased the number of papers retrieved (Jenuwine & Floyd, 2004). Similarly, expanding the search to include grey literature may have resulted in more papers for review.

Future Research

Future research may wish to assess whether breast cancer awareness initiatives improve mammography attendance for women with intellectual disabilities (and by which mechanisms this is achieved). For example, does greater awareness of breast cancer / screening improve self-efficacy? Focus groups could consider the specific information that women with intellectual disabilities feel would better prepare them for mammography screening, and how to deliver it. Research could explore how family members manage, and navigate, the competing imperatives of protecting their loved one from harm, whilst potentially supporting their attendance at a mammography procedure that may inflict physical and psychological harm upon their loved one.

Conclusions

This meta-synthesis provides a review of the available qualitative research concerning the perceived physical and psychosocial barriers to mammography access for women with intellectual disabilities, from the perspectives of women with intellectual disabilities, HCPs, paid carers, and family members. Mammography screening elicits anxiety from both women with intellectual disabilities, and their supporters (whether paid, family, or HCP). Local services should develop bespoke intellectual disabilities breast cancer screening care pathways, which recognise both evidence-based approaches and local needs and resources, so that minimum standards of delivery can be established, with clearly defined roles and responsibilities for HCPs, and the expectations of paid cares and family members alike. Care pathways could be supported by a formulation-based approach which explores what women with intellectual disabilities understand about breast cancer and the screening process, what they would like to know, what are their fears, and where are their learning strengths / challenges.

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Conflict of Interest

No conflict of interest to declare.

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