Introduction

Globally, breast cancer affects one in eight women during their lifetime[1], and often requires invasive investigations and treatments[2]. People with breast cancer have complex physical, psychological, and social needs beyond their cancer diagnosis and throughout treatment[3-6.] In the United Kingdom (UK), the National Health Service (NHS) Long Term Plan emphasises the need to offer support in line with the national 'personalised care' agenda, which focuses on the relationship between healthcare professionals, systems of care and those requiring care[7]. In the context of cancer, this support includes holistic needs assessment (HNA) (also known as personalised care and support planning), end of treatment summaries, cancer care review and health and wellbeing information[8]. HNAs are central to personalised care, and involve conducting individualised assessments of people's needs, which translate into care plans and actions to address concerns. Although many forms of HNA exist, Macmillan Cancer Support's electronic HNA (eHNA) is widely adopted in the UK. The eHNA is an online platform which hosts several HNA tools, accessible by both patients and staff to complete assessments or write care plans.

Despite notable benefits of HNAs, such as providing a forum for people to discuss their concerns, and empowering self-management, the small evidence-base highlighting user perspectives of HNAs suggests challenges with its implementation, day-to-day use, and outcomes. For example, management and peer support are essential for the successful set up of HNAs, yet staff resistance to its use was found in many cases[9-10]. Also, staff describe challenges in identifying meaningful times and locations to undertake HNAs[9,11-12], as well as how to balance addressing needs identified with workload pressures[9-10,13-14.]

Furthermore, technology can create challenges for healthcare professionals and people with cancer[9,15-16]. Some staff lack the confidence to discuss the concerns people raised in their HNAs, or perceive items on the HNA to be beyond their conventional nursing job role (e.g., advising on financial concerns)[10,13]. Minimal research has considered experiences of HNAs from the perspective of people with breast cancer, but one study highlighted variable opinions, stating that several participants viewed the assessment's purpose as being for research, and having minimal benefit to them[17]. Other studies on patients' experiences of HNAs (various cancer types) highlight that people do not consistently disclose concerns during HNAs, for reasons such as fear of particular outcomes (such as social services involvement), perceptions of wasting staff time, misunderstanding the HNA's purpose or their expectations[10,17-18].

Overall, little is known about user perspectives of HNAs, and how valuable its contribution is to those undergoing and delivering the assessment. In the UK, Macmillan Cancer Support's eHNA is widely adopted but lacks research-based evaluation of its use.

Normalisation Process Theory

To investigate the eHNA, principles of Normalisation Process Theory (NPT) were used. This theory categorises and explains key factors which promote or constrain the implementation or integration of innovation into healthcare settings[19]. This theory was utilised based on its compatibility with qualitative research, usefulness to explore the barriers and facilitators to implementation of interventions, and the ability to consider the social processes which appear to influence success[19]. As a relatively new intervention, the process of embedding eHNA into day-to-day practice aligned with many of NPT's concepts.

Aims

The research question was ‘How does the eHNA contribute to the assessment and support of the holistic needs of women living with or beyond breast cancer?’ Primarily, the aims were to understand perceptions of the eHNA and associated care plans, and the contribution of these (if any) to women's experiences of support, from both staff and women with cancer's perspectives. Furthermore, the study sought to identify facilitators or barriers to the eHNA's use.

Methods

Design

A qualitative case study design was chosen, adopting the approach described by Robert Stake[20], utilising semi-structured interviews, non-participant observations and document analysis data collection techniques. This offered flexibility and opportunities to corroborate findings through data triangulation[21]. Stake’s approach to case study allows for flexibility in design and analysis, aligning with a constructivist epistemology[20]. This is facilitated through presenting detailed, narrative accounts of participants’ experiences using a variety of data collection methods, allowing the reader to arrive at their own interpretations and generalisations.

Case Study Settings

Following full Research Ethics Committee and Health Research Authority ethical approval, two case studies were developed, by purposefully selecting two secondary healthcare settings which had embedded Macmillan Cancer Support's eHNA within their breast cancer service and were regular users of this (based on data obtained from Macmillan Cancer Support, which highlighted

NHS Trusts with high usage). The two sites chosen were similar in size, and both delivered care to patients with breast cancer from two main hospital sites, meaning four hospitals were included in total. Patient and public involvement and engagement (PPIE) activities informed decisions made throughout the study. Site access was obtained through local research and development departments, engagement with senior staff in the cancer teams and delivering presentations to obtain greater buy-in from staff.

Table 1. HNA Implementation in Case Study Settings

Sampling and Recruitment

Purposive sampling was used to identify participants, and 24 women with cancer and 24 staff involved in eHNA implementation or delivery were recruited. Staff were included to present a perspective on the factors influencing how the eHNA was delivered to women, and the subsequent outcomes from these. This was achieved through letters of invitation sent to approximately 90 women with cancer, inviting them to contact the researcher directly, and conducting local presentations and discussion with staff to aid recruitment. In both case studies, eHNAs were largely delivered by 'the breast teams', which incorporated specialist Breast Care Nurses (BCNs), and Support Workers with varying job titles, but other roles such as Radiographers and Project Managers were recruited to the study where relevant.

Table 2. Case Study Participants

Data Collection

Semi-structured interviews and observations were undertaken by one researcher (LB) between April and December 2019. All participants took part in one face-to-face interview either in the hospital or their own homes (for women with cancer, based on personal preference), and three women with cancer also underwent a further, brief telephone interview to discuss any outcomes from their eHNA, which had occurred since the initial conversation (this was undertaken when the initial face-to-face interview occurred in close proximity to the eHNA itself, to see if additional outcomes occurred over time). Women's interviews ranged from 18-77 minutes, and staff interviews were 20-69 minutes. Observations were also undertaken of the eHNA being completed, which was possible with seven participants, based on variability and scheduling in the eHNA's delivery. The process involved a member of the research team (LB) attending clinic appointments where eHNAs were being undertaken, observing the full appointment, and taking detailed notes with the assistance of an observation guide. The observation guide was adapted from two examples that outlined key areas of focus, such as body language and verbal discussion[22-23]. The guides developed for both the interview and observation aspects of the study were created with PPIE input

Documents were also collected and accessed through the usual care provider at the relevant study site. Documents provided included copies of generic patient correspondence used within their organisation (including the hospitals' letters of invitation to complete the eHNA, a Macmillan Cancer Support eHNA information leaflet, an eHNA online access card), and copies of applicable eHNA care plans completed for the women recruited.

Data Analysis

Framework Analysis[24] was adopted, as it maintains grounding within the original accounts of participants, is systematic and is useful for easily retrieving data in cross-case analysis[24]. For the initial data management processes, familiarisation, and immersion in the data by the researcher (LB) led to the identification of recurrent concepts, which were refined and developed into a thematic index, displayed through a series of matrices[25]. Data analysis was divided into two stages, the first of which was 'descriptive accounts', (reducing data to create meaningful ‘classes' and ‘categories’, followed by the development of multidimensional groupings to divide and organise phenomena, called 'typologies')[25]. The second aspect of analysis was 'explanatory accounts', which identifies connections in the data to develop ‘explicit’ (openly stated by participants) and ‘implicit’ (inferred by participants) explanations, supported by techniques which enable the development of conclusions[25]. Furthermore, triangulation of findings[26] within and between case studies was undertaken, to confirm findings. ‘Worksheets’ (charts containing key themes from each case so comparison can occur) were developed by the researcher (LB) to map out key findings from each case study and generate overall study conclusions. All data collected in the study was mapped using this process, which included notes taken from what occurred during observations, or the verbatim text used in documents, to further corroborate or oppose interview data.

Table 3. Framework Analysis Process

Study findings were also considered by using NPT's constructs as an additional lens through which to view these overarching findings, which assisted in the development and interpretation of study conclusions.

Table 4. NPT Constructs

Rigor was considered from various perspectives within the study, maintaining credibility through use of the patients' own words in reporting of findings. Transferability and dependability of study data were established through detailed description of each case (including participant demographics and data collection methods adopted), alongside the detailed framework analysis processes outlined above, allowing for clarity if the methods were to be replicated. For confirmability, reflexivity was undertaken throughout the research process, using an understanding of five common variants[27] to mitigate effects of the researchers on the data collection and analysis processes.

Results

Framework Analysis processes[24] identified three overarching factors which appeared to influence the eHNA's contribution to women's experiences of support, each with sub-categories. These factors related to the perceptions and judgements of the individual undergoing the assessment, those of the staff member completing it, and the wider organisational context in which the eHNA was completed.

Table 5. Factors influencing the eHNA's contribution

1. How women's views and judgements influenced their perceptions of the eHNA

From the perspective of women, the eHNA's contribution ranged from beneficial to potentially harmful, introducing a paradox between the aims of the eHNA as a supportive tool, and the reality of its use. Women's experience appeared to be on a spectrum, dependent on various factors, such as their intentions, state of mind, priorities, self-confidence and how they understood the assessment. Overall, there appeared to be increasingly negative perceptions reported by the women in CS1 than in CS2, as most women in CS1 reported that the eHNA was either not useful, or had minimal benefit to them at the point it was done.

Intentions

Many women indicated their intentions towards an eHNA conversation, such as intentions to not fully disclose their concerns based on their willingness to explore these, or opposing intentions to be entirely honest, for their own benefit, *"I wanted to be truthful for it to be of any use, but I didn't want to be completely truthful in case it led anywhere, there were things that I felt, but I didn't want to discuss them, (0208P, CS2).* These considerations also influenced participants' scoring of eHNA concerns in some cases.

State of Mind and Priorities

Participants' intentions appeared closely connected to their state of mind and priorities at the point eHNA was completed, regarding how much support they felt they required, whether they felt emotionally able to process the eHNA, and perceptions of their ability to self-manage. "*I wasn't in the frame of mind to read everything that I had, I just wanted to get it over." (0104P,*

CS1). Consequently, most participants felt the point of diagnosis was an overwhelming time to complete the eHNA, which affected engagement. Further influences on participants' engagement with the assessment included whether their priority was emotional support or other external assistance the eHNA could highlight, or if wider factors were given precedence, such as getting home from the hospital for a dependent family member, or prioritising full-time work over support for financial reasons. *"To be honest I haven't done any of that… I feel that it's gonna take me away from my husband when he needs my full attention" (0109P, CS1), "I think I was focused on my next job was to go and see the consultant… and she's going to assess me and she'll look at my scar, but that was more important to me, so maybe the timing of the two, I think left to it on my own, I would have taken in more really, I think I was distracted." (0208P, CS2).*

However, even for participants who reported not requiring support, many felt that the assessment was meaningful 'in principle', as it created a safety net to stay connected to support, particularly if the eHNA was repeated: *"At least somewhere you're in the system… I think it's helpful in that it shows there is a sort of care system around you potentially ready to help you." (0101P, CS1).*

Confidence

Several participants reported a lack of confidence in completing an eHNA, and knowing which concerns were appropriate to raise with staff. Participants indirectly sought guidance with this, either by voicing their experiences of a particular concern (and waiting for staff responses), or by directly asking questions. Furthermore, this confidence appeared connected to participants' desire to complete the eHNA in the 'correct' way, or in a way which was useful to other people, *"I felt guilty 'cause everything was 'no'… I thought perhaps I was wasting her time." (0201P, CS2). "I should take it up because it was being offered, and I might need it, and maybe in the past there*

hadn't been anything like that, and people had to struggle on, on their own." (0105P, CS1). Several participants alluded to not wishing to be a 'nuisance' or burden to staff through the eHNA, and indicated feeling compelled to complete it, either through believing it was an expectation, or that the data they provided would help other women. This was also highlighted through observational data, for example where women apologised for having ticked so few concerns on their eHNAs, and feeling that they were being unhelpful (0201P, CS2, 0209P, CS2).

Making Sense

Participants' interpretation of the eHNA was one of the most significant influencers on how meaningful it was to them. For example, misinterpretation led to disengagement or an unclear understanding of what the assessment offered in some cases, such as assuming it was related to the provision of alternative therapies rather than a supportive conversation *"I'm quite a holistic person myself, and I've used alternative therapies before." (0102P, CS1).* However, this understanding also led to opposing expectations in some incidences. One participant was pleasantly surprised by the support offered following the eHNA; others reported unmet expectations and disappointment: *"I was quite excited to fill it in in the first place, thinking this is my chance to sort a few things out, but it just wasn't there... so for me it didn't fulfil any of my expectations or needs." (0203P, CS2).*

Several participants appeared uncertain of how to fill in their eHNAs, and during their observations, three of these requested clarity in the correct way to complete it (0201P, 0202P, 0209P). These participants were exclusively from CS2, which may be due to most CS1

participants completing their eHNAs at home without the presence of a staff member, and were therefore not observed in most cases.

2. How the Staff Member's Views Influenced their Perceptions of the eHNA

As with the views of women, staff opinions of the eHNA were dependent on multiple influencing factors, determined by their own views and judgements. Many staff across both sites felt the process required improvement, and negative views towards the assessment were found more commonly in CS1 than CS2.

Vulnerability

For participants with a nursing background, many felt that the eHNA presented a threat to their role, as use of the tool suggested they were not undertaking their jobs effectively. Views were mixed on what should and should not be documented in an eHNA care plan, and some participants raised concerns about safety when providing formal documentation to women, *"She's discussed her suicidal thoughts with me… there's a little bit of a concern that you're giving her a licence do something by saying we've spoken about it." (0102S, CS1).*

Uncertainty and Understanding

Many staff indicated uncertainty around the 'correct' way to conduct an eHNA and how to discuss women's concerns, and their interpretations of this differed widely. This included interpretations of how to 'solve' concerns when no clear solution was available, *"I do find it hard sometimes because I just feel I've not done enough... I can't solve it." (0201S, CS2).* For some,

their orientation to the eHNA had been brief or unclear, which affected their confidence in how best to support people following an assessment *"We were never given like a proper introduction to this is why we do it and this is how you do it… I don't feel like we've had proper training, on like how we can like deal with things that people bring up." (0205S, CS2).* This view was particularly evident among staff with fewer years of experience, and those who were not nurses.

Almost all staff believed that the eHNA caused people to raise concerns which had little significance to their cancer diagnosis. *"Are you concerned about a cough, yes I've had a cough for ten years so I'm going to score it, but it's not actually something that's in the back of their head or a priority or even a concern, but because the form has prompted them, they'll then tick it." (0101S, CS1).*

Priorities

Many participants indicated that eHNAs were low priority tasks, and that Support Workers had significantly more time to undertake these than other staff. Views varied towards the benefits and burdens of the assessment and its implementation, but the existence of target eHNA completion metrics presented pressure and feelings of obligation, which affected quality of assessments for some staff. This view was more evident in CS1 discussions than CS2. *"It becomes a tick-box exercise, it can water down the content of the HNAs because people are trying to fit them in within a certain time period, and we probably get more declines as a result of patients not being ready at that point." (0103S, CS1).*

Alongside their own priorities, staff described altering timing and venue of eHNA assessments based on what they expected women to find important, such as reducing the frequency of hospital visits. *"They don't want to make another trip to see us… Practically, it's over the*

'phone." (0108S, CS1). Despite this, many staff remained uncertain about what women's preferences actually were with regards to when, where and how to do the assessment, and speculated about whether women would desire privacy, online or paper assessments, *"I think they prefer doing that than doing it at home to be honest, but whether when we're sat there with them puts them on their guard, I don't know." (0201S, CS2).*

3. The influence of Organisational Context and Implementation on the eHNA's Contribution

A further influence on participants' perceptions of the eHNA appeared contingent on the organisational structure and processes within which it was situated.

Delivery Priorities

How the organisation approached eHNA implementation seemed connected to staff views towards it. This included whether an emphasis was placed on achieving targets around eHNA completion, and the leadership surrounding this. *"If you compare with other cancer sites, the lead Clinical Nurse Specialists that are really engaged with HNA... then it works, but if you've got resistance from your leader, it filters through." (0106S, CS1).* Each organisation's leadership influenced how the eHNA was implemented. In CS1 staff talked about targets, pressures and indicated a lack of autonomy to change practice, whereas CS2 staff felt able to make changes depending on the success of eHNA delivery methods, *"We found it failed, it just didn't work because they weren't in the right mindset... so then we tried it at post-op." (0207S, CS2).*

Blame Culture

Participants discussed completion of eHNA care plans, and their value as evidence of the support they had provided. Many staff interviews indicated that evidencing their actions was useful if they were challenged by people they cared for, *"I suppose if they've got a care plan and it's on there what they've gotta do, then they can't come back to me and say you didn't tell me that." (0102S, CS1),* or if there was an issue which meant they needed to defend what they had done, *"It's quite hard to say that you've done something if you haven't used a tool, or you haven't got something to back you up." (0108S, CS1).* There was also a notable difference between the care plans analysed in CS1 and CS2, with more positive attitudes towards these noted by the women and staff in CS2. Care plans in CS1 were also found to include more incidences of medical jargon and acronyms.

Hierarchies

Organisational hierarchy or culture within staff structures appeared to influence how successfully the eHNA was implemented, with some staff being resistant to change: *"It's things like, "We don't need to do that, we've been doing this for years," and it's almost against me as if I'm the person bringing this thing in." (0105S, CS1).* Some staff valued the scoring system within the eHNA (i.e., using scores to determine who can address concerns, such as scores above five should be reviewed by a registered professional, and below five could be a support worker), *"Everything above five really should go back to either the breast care nurse, or the oncology team." (0107S, CS1).* However, data did not suggest that one staff role performed increasingly meaningful eHNAs over another.

Whilst differences were found in the perceived value and attitudes towards the eHNA in CS1 and CS2, NPT also highlighted the areas of implementation which were absent in these cases,

including staff buy-in, resource allocation and reflective activities. Reflection appeared increasingly absent in CS1 than CS2, where the team culture and genuine belief in the eHNA's value were not apparent.

Discussion

The study demonstrates that women's intentions, priorities, confidence and understanding of the eHNA influenced their perceptions of its value, and how they engaged with it. These perceptions were further driven by the eHNA's delivery, including the priorities, and understanding of the staff member delivering the assessment, and the culture within the organisation.

Women's concerns were not consistently disclosed on eHNAs. There is limited evidence around people's intentions in clinical encounters, but entering consultations with the aim of withholding psychological concerns has been previously identified[28]. In the current study, reasons for non-disclosure included expectations of judgement from staff, not wishing to burden staff, or needing to prioritise others (if they were a carer). Other studies have found that patients lack trust towards staff to reveal embarrassing concerns[29], fear being judged, disturbing busy staff, or want to avoid being seen as 'difficult'[30-32]. The 'hospital-patient role' and power dynamics (how unequal power affects the relationship between two people)[33] have been found to influence patients' behaviours, such as acting according to what they believed the organisation desired to avoid negative consequences[34-35]. Similarly, this study found that many women completed eHNAs because they felt obliged to, appeared eager to please staff, and made references to being a 'nuisance'.

In our sample, women expressed varied preferences for how eHNAs should be conducted, such as timing, location, and what purpose it served for them. Firstly, participants felt that the time of

diagnosis was too overwhelming, which is echoed within literature[36-37]. Secondly, staff perceptions of women's priorities around eHNA practicalities varied considerably, and no consensus was reached about the 'right' time and place to do eHNAs, which is congruent with wider literature[9,11-12,38.] We found that staff assumptions about patient preferences are not consistent with the patient's own reports of their preferences, and this has been stated previously[39].

Women's understanding of the eHNA was variable in the study, such as whether it was optional or what expected outcomes would be. Misunderstanding elements of the HNA process or purpose has been shown elsewhere, for patients[40-41], and staff, who report insufficient training in some cases[10,13]. Staff in our sample reported using the eHNA through a sense of obligation, which increased their resistance to delivering it (at least initially). Resistance to change is common with the introduction of new interventions, which can be perceived as threatening and disruptive[42-43]. Organisational cultural factors were also present in study sites, where shared norms and values in the organisation influenced behaviours[44]. This was further highlighted through use of NPT, which revealed a lack of depth in eHNA implementation in these organisations, based on social processes which appeared not to have taken place, (such as reflexive monitoring to improve practices)[19]. In turn, this hindered how well the process had been embedded, and its goal of becoming 'business as usual'. Here, staff described feeling that eHNA performance targets were not meaningful, and blame cultures existed. Performance indicators and targets are deemed necessary for the functioning of any complex system[45], but there is a danger of measuring aspects of care which are simple to quantify, rather than those which suggest meaningful care[46-47].

Delivery of eHNAs which were not fully understood, not delivered in a meaningful way, or were influenced by the desire to please staff, meant that in some cases, the eHNA's contribution to women's experiences of support was minimal or negative. This finding is consistent with the view that how HNAs are implemented is as important as the outcomes[48].

Limitations

The small study sample enabled in-depth exploration of perspectives, but may not reflect the views of people with different characteristics, or different experiences of care. Furthermore, practicalities (such as unplanned eHNAs which could not be attended) made it challenging to undertake follow-up interviews and observations in the study and there was a disparity in numbers of observations in each case study. The dual identity of the researcher (a nurse with subject matter experience) may have influenced data collection and analysis activities, although reflexivity was undertaken throughout to minimise this.

Conclusion

This study shows that the eHNA can make a positive contribution to the experiences of women with breast cancer and the support they receive. However, if not completed under the 'right' set of circumstances, its contribution can be minimal, or even negative. Women require greater explanation of the HNA's context before completing one, including its purpose, value, and their freedom to report or not report relevant concerns. In the organisations in this study where the eHNA had minimal or a negative contribution, NPT emphasised that implementation of the tool appeared superficial, and not yet business as usual. Therefore, organisational cultural factors play a key role in the delivery of the eHNA, and its subsequent success. The potential of the eHNA

juxtaposed against the reality of its use suggests a need for culture change, moving away from task-orientated approaches, and towards the facilitation of meaningful, personalised, conversations. In practice settings, a greater focus is needed on a robust process of addressing concerns from assessment to action, ensuring that staff are adequately trained on supporting needs, and patients' are not left disappointed by the process. Quality should be prioritised over target achievement, and training of healthcare professionals should be centred around delivering HNAs in a meaningful way, that focuses on individual patient benefit.

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Table Legend

Table Number	Table Title
Table 1	HNA Implementation in Case Study Settings
Table 2	Case Study Participants
Table 3	Framework Analysis Process
Table 4	NPT Constructs