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Research Article

A Sculptured Journey: A Photovoice Study About Information Sharing Among Unpaid Carers in England

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This article explores the critical and often overwhelming task faced by unpaid carers: gathering and interpreting complex information so that health and social care systems can be accessed and understood. Based on a qualitative study centering the views and voices of unpaid carers, it provides a rich analysis of how carers share and interpret information within carer-centered group activities, offering practical insights for both practitioners and carers. In England, the Care Act 2014 places legal duties on local governments to provide information; however, this is often reduced to "signposting," leaving carers with unresolved questions and significant frustration. Consequently, carers frequently rely on one another to fill these gaps and support those they care for. Adopting a critical realist ontology and a social constructionist epistemology, this study balances the external realities of the Care Act with the subjective experiences of unpaid carers. Using photovoice, a method combining visual and narrative techniques, the study enabled carers to convey their approaches to information sharing. Reflexive thematic analysis identified the key theme of "an information highway: a sculptured journey" along with its subtheme, "an information bridge." This analysis deepens understanding of how and when carers share information effectively, addressing an underexplored area within the literature on carer-centered group activities. It illustrates how carer-led information sharing enhances carers' knowledge of rights and resources while fostering a sense of connection and support.

Keywords: information sharing; photovoice; social policy; the Care Act 2014; unpaid carers

Summary

- What is known about this topic?
  - Carers regularly exchange information based on their experiences in shared meetups.
  - In England, the Care Act 2014's duty to provide information is often implemented as "signposting" by local authorities.
  - The information carers need to carry out their roles, which are broad, complex, and frequently difficult to access.
- What this paper adds?
  - Carers often find themselves unexpectedly developing information-gathering skills, although some struggle to do so.
  - Trust and emotional safety foster more effective information sharing between carers.
  - Well-facilitated and resourced group activities may help reduce the risk of inadvertently sharing inaccurate information.

1. Introduction

Unpaid carers globally play a vital role in supporting individuals with diverse needs and must often navigate complex health and social care systems to access essential resources [1]. The analysis explored in this article forms part of a wider study investigating how carer-centered group activities intersect with the Care Act 2014 in England. This article focuses specifically on the Care Act's legal duty to provide information and advice, exploring how this intersects with carers' own informal information sharing in community spaces, and how such exchanges might support or complement formal provision.

The United Kingdom introduced the Pre-Care Act, a personalized budget system for individuals who needed social care [2]. However, Woolham et al. [3] and others (e.g., [2, 4]) argued that the administrative and financial burden of this policy shift largely fell to their carers who had to understand how processes worked and be accountable for the money. This policy trend helps explain why gathering and sharing information are so critical to many carers' lives.

Internationally, legislative recognition for carers varies considerably. Countries such as Australia and the United States provide partial frameworks of support, with Australia's Carer Recognition Act 2010 offering policy guidelines, and United States' programs such as the National Family Caregiver Support Program [5] delivering limited respite services. In contrast, many countries in the Global South lack formal legal frameworks altogether [6]. Although few international policies explicitly set out duties around the provision of information to carers, emerging research highlights the importance of recognizing how cultural and structural factors shape carers' experiences and support needs [6, 7]. This suggests that caution is needed when making generalizations across national contexts.

The Care Act 2014 in England introduced a legal framework aimed at supporting adults with care needs and the unpaid carers who assist them. One of its universal duties is to provide carers with information and advice, including on services, entitlements, and preventative support [8]. However, the implementation of this duty has often been limited to signposting, particularly through local authority websites [9, 10]. The result is often fragmented, inconsistent, and inaccessible information systems that carers must navigate alone [11, 12].

In many areas, local governments outsource their information and advice responsibilities under the Care Act to not-for-profit organizations that also facilitate group support for carers [9, 13, 14]. These community spaces, where carers gather for mutual support, are described here as carer-centered group activities. They may include informal meetups, well-being-focused sessions, and information sharing. Although studies have acknowledged the role of carer-centered group activities in enabling the exchange of practical knowledge [14–16], few have explored how these mutual exchanges function, or why carers may find them more relevant, accessible, or emotionally resonant than formal systems. This article focuses on the lived experiences of carers participating in carer-centered group activities and explores the emotional, practical, and social value of information sharing in these contexts, particularly in navigating structural challenges.

2. Methodology

This research is grounded in a critical realist ontology and a social constructionist epistemology. Critical realism acknowledges an external reality that is always mediated through human perspectives [17], while social constructionism highlights how concepts such as "carer" and "support" are shaped by shared social meanings and institutional discourses [18]. These philosophical foundations support an exploration of carers' lived experiences of information sharing within carer-centered group activities, as situated in the broader policy context of the Care Act 2014.

The specific aim of this article is to explore how carers share and interpret information within carer-centered group activities, and how this may support the Care Act's universal information and advice duties in practice. It focuses on one theme from a broader dataset, using participant responses to a single prompt that explored the nature and sources of helpful information. This prompt was one of the three used in the wider study to explore carers' experiences of information sharing, well-being, and statutory processes under the Care Act. It was selected because it directly supports the article's aim and enables in-depth consideration of how informal, carer-led information sharing operates in practice. The guiding research question was as follows: "Of information about your caring role that you have found helpful, what has been most useful and who gave it to you?"

This article focuses on the voices of unpaid carers and the systemic challenges they encounter in accessing information under the Care Act. Photovoice is a visual method that enables participants to express aspects of their experience through photographs and reflective discussion [19]. Metaphorical images are frequently the result of photovoice [20]. The method was selected for this study as it supports autonomous engagement and can help surface perspectives that might otherwise remain hidden [19, 21]. Carers were invited to take photographs relating to the research question and explore their meanings during an interview. This method aligns with a critical realist approach, which enables carers to visually represent aspects of systemic reality as experienced from their own perspectives.

The data were analyzed using reflexive thematic analysis [17], a method well-suited for capturing complex, nuanced patterns within qualitative datasets. Reflexive thematic analysis' flexibility allowed for a recursive analysis, where themes were refined through multiple cycles of coding, reviewing, and thematic clustering, enabling a richer understanding of participants' experiences of information sharing. This approach aligned with the study's social constructionist epistemology and was selected for its capacity to explore how carers collectively construct meaning through shared information practices within socially situated contexts.

Although the participants were free to choose their own photographs within the framework of the research, offering

opportunities for self-expression, this study was not a fully participatory one [19]. This aligns with reflexive thematic analysis, which is founded on researcher subjectivity and creative interpretation [17]. In addition, carers' time constraints and unpredictable responsibilities made sustained coanalytical involvement unfeasible [22].

NVivo software was used to facilitate the coding process, with visual data and interview transcripts coded separately before being brought together in analysis to allow meaningful integration of visual and narrative insights. This rigorous approach supported fresh insights into an underresearched area, with the phases of reflexive thematic analysis facilitating a deep engagement with the data to construct patterns and subtleties that may otherwise have gone unexplored [17]. See the Supporting Information for additional detail on the analytic process and theme development.

3. Ethical Approval and Dilemmas

Ethical approval for the study was received from the University of Derby in May 2023. All participants gave informed consent to participate in the study and for their anonymized quotes and photos to be used in future publications. The Participant Information Sheet provided a clear outline of the measures in place to support participants and protect their well-being throughout the study.

Due to data protection and privacy considerations, a decision was made at the research design stage to ask participants not to take photos of anyone identifiable.

4. Recruitment

Over 50 carers expressed an initial interest in the project. The research design indicated that 20 carers would be sufficient, and 21 were recruited between May 2023 and July 2023 from a national network of commissioners of carer services and the organizations they fund. This number was guided by the principle of information power, which suggests that fewer participants may be needed when the study aim is focused and the dataset rich [23]. Participants were given 14 days to withdraw any of the photos or from taking part completely following the interview. However, no participant withdrew.

5. Data Generation

Participants submitted up to 10 photographs of their choice, which were then used to guide a semistructured interview. These were emailed in advance of the interview, which was conducted either online or in-person, depending on each participant's preference. The interviews lasted between 40 min and 1 hour, with images displayed on screen to support reflection and memory [24] All interviews were conducted by the author, who drew on experiential knowledge to foster trust and rapport.

The photos and interview transcripts together formed the dataset for the project. Transcripts were anonymized immediately, with participants asked in advance to select a made-up name for use in publication. All data was securely stored in password-protected folders.

6. Reflexive Thematic Analysis Reporting Guidelines

This article draws on Braun and Clarke's [25] reporting guidelines produced for reflexive thematic analysis studies. Reflexive thematic analysis is a fully qualitative approach, and articles using this method may be structured differently from those based on more procedural forms of qualitative research or from mixed-methods studies [25]. Therefore, the language and assumptions used reflect a set of values compatible with methodological coherence. For example, this article uses terms such as "data generation" instead of "data collection" to emphasize the researcher's active role, and "analysis" rather than "findings" or "results" to reflect the interpretive nature of qualitative work. This aligns with the guidance that qualitative studies are not reproducible and do not aim to uncover objective "truths" within a dataset [25]. Another key feature of reflexive thematic analysis is the integration of themes with other literature. Braun and Clarke [17] argue that "generalizability" in fully qualitative studies refers not to statistical representativeness but to how well the analysis resonates with, or can inform, broader theoretical and practical understandings. When analyses are contextualized within theory and existing studies, they help readers see how the insights might extend beyond the immediate dataset [17].

Reflexive practice was used throughout to consider how the researcher's assumptions, experiences, and positionality influenced the construction of meaning. In line with Braun and Clarke's [25] guidance on quality in reflexive thematic analysis, the analytic process prioritized depth, transparency, and recognition of the researcher's active role in knowledge production.

7. Demographic Information

Table 1 shows the demographic information about the participants. This information is presented contextually rather than from a positivist notion of representation [17]. A brief overview helps situate the diversity of participants and the contexts in which they discussed information sharing as carers. Inclusion criteria focused on those providing sustained support over time, ensuring that the insights shared were grounded in lived, ongoing engagement with complex health and social care systems.

8. Thematic Analysis

This theme, "information highway: a sculptured journey," explores the central role of information in participants' lives, particularly how it arrived from multiple sources in overwhelming and unstructured ways. In line with previous literature (e.g., [11]), participants described a sense of being inundated by information while simultaneously being left to navigate it alone. From this position of overload, some shaped their own "DIY kits" of essential knowledge as they moved through different stages of caring, constantly adapting to new needs. The metaphor of a "sculptured journey" reflects the active, resourceful effort these

Table 1: Carer participant demographics.

Name carers chose	Male/female	Age-range	Disability	Race/ethnicity
Sam	F	41–55	N	White, United Kingdom
Brenda	F	56–65	N	White, United Kingdom
Esmeralda	F	56–65	Y	White, United Kingdom
Milo	M	30–40	Y	White, United Kingdom
Vernon	M	56–65	Y	White, United Kingdom
David	M	30–40	Y	White, United Kingdom
Candy	F	56–65	N	White, United Kingdom
Affinity	F	41–55	Y	White, United Kingdom
Lovena	F	56–65	Y	Black British Caribbean
Leticia	F	41–55	N	White, United Kingdom
Meduck	M	56–65	N	White, United Kingdom
Skye	F	66–75	N	White, United Kingdom
Beth	F	56–65	N	Mixed heritage, White/Caribbean
Jill	F	56–65	N	White, United Kingdom
Mummymoo	F	56–65	N	White, United Kingdom
Pearl	F	56–65	Y	Mixed heritage
Tom	M	56–65	N	White, United Kingdom
Brahma	M	41–55	N	Asian, Indian
Ann	F	56–65	N	White, United Kingdom
Bina	F	Over 75	Maybe	British, Indian
Sally	F	41–55	N	White, United Kingdom

participants undertook in filtering and assembling relevant information to support those they cared for [2, 3, 26]. The subtheme "Information bridge" highlights how other carers, informally or through carer-centered group activities, helped with the task of assimilating information.

This pattern was evident in participants' descriptions of being bombarded with a range of information, some of which may have been useful, while other parts were not. As a result, participants were responsible for deciding what was useful and what was not. Meyer's [11] study similarly found that local authorities gave standardized, complex information without consideration of how carers would receive it.

The phenomenon was visually captured by Ann in her photo of a cliff face (Figure 1).

Ann: The bricks and the cliff face is that you just gather all this information that just piles on. (. . .) Just all piling up on top of each other; the information.

Ann's visual metaphor conveys an image of information heaping on top of carers in a haphazard and disordered way, with no clear sense of whether the information received or gathered will ever prove useful. Letitia and Jill described the experience of information gathering verbally as

Letitia: They'll give you leaflets for this and leaflets for that. (. . .). Somehow I would read them emails and get. . . you know. . . to look at them.

Jill: All the millions of words out there that are useful to carers. All the jargon, all the complexity of policies and processes and legal framework. (. . .), the system is massive and complex and incredibly difficult to navigate.

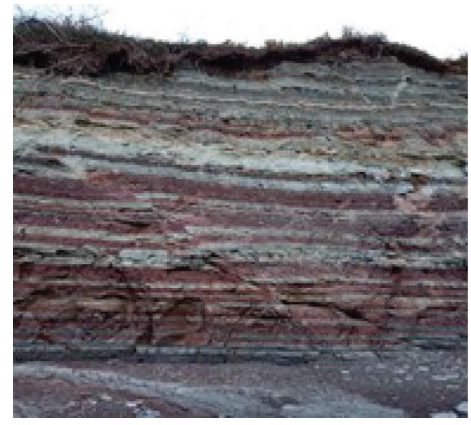

Figure 1: Participant-generated photograph accompanying quote and analysis.

Jill's account suggests that the biggest challenge for carers is the complex systems they need to understand and use either on behalf of themselves or their loved ones. All three participants convey a sense of information-overload with Sam identifying the dangers of being bombarded with information.

Sam: Lots of people have advice for you (. . .). I don't take on board everything that everybody tells me.

Participants explained that, as they became familiar with the caring journey, it began to occur to them that an essential skill was gathering the right information at the right time. They were not prepared for the need to develop this skill, and some expressed greater concern than others about their ability to do so.

Tom, for example, described how he came to understand that processing information was central to the caring role, despite feeling unprepared for it.

Tom: when you are doing something within the caring role, you have to do things like filling forms and sign this and sorting things out. That's really office work. You know, that's not really what I'm born to do, so I'm gonna struggle with it myself.

Tom believed that information management was beyond his skillset, which he saw as more hands-on and aligned with the practical aspects of caring.

Tom: I'm good with my hands, working with my hands and don't mind the caring role. You have to assess what you're born to do you know? What your position in life is.

It dawned on participants, as they became more familiar with the requirements of the role, that information-gathering was more complex and difficult than they had understood, and that no professional was available to help them with it. Mummymoo, for example, explained it like this,

Mummymoo: No one was throwing arrows at me, saying "go this way, go this way." (. . .) I had to do it all myself, (. . .).

Meyer [11] also highlights that carers do not expect, when they begin the role, that their knowledge base will need to expand and deepen in order to provide care and ensure their own needs are met. She expresses concern that local governments tend to adopt a "one-size-fits-all" approach (p.832) to information and advice, even though carers need more individualized and accessible guidance.

Participants agreed with analysis from other studies (e.g., [9, 10]),, that local governments appear to be satisfied that "signposting" is an acceptable way of interpreting the information and advice duties under the Care Act. Yet, participants expressed annoyance that this was the limit of help on offer and, for many, signposting simply served as a further source of frustration.

Esmeralda illustrated the prominence of signposting in her interactions with professionals by choosing a visual image of a public footpath postpointing toward nowhere (Figure 2).

Esmeralda: virtually everything is just signposting from the supposed support organizations. (. . .). "And the answer is "no, we don't do that." It's always "we don't do that," or "we'll refer you to somebody else who does."

Esmeralda described a specific instance where she contacted a carer organization with a query and was repeatedly signposted between different services. She ended up back where she started, without ever receiving the information she needed.

FIGURE 2: Participant-created image shared during photovoice interview.

Participants emphasized the importance of making sense of the vast amount of information they encountered in their caring roles. Some described how, over time, they developed strategies to manage and navigate this information in ways that worked for them. Ann illustrated this through a photo of a Lego kit, symbolizing how she sculpted her own journey (Figure 3).

Ann: You just pluck out the bits that you want (. . .) build up what you want with your own LEGO of what's interesting, helpful.

Ann's photo metaphor captured the messiness described by her and other participants, reflecting how information often came at them in disorganized and overwhelming ways. By choosing a Lego analogy, Ann conveyed how she could piece together a structure that suited her needs, one she had shaped herself and could reshape as those needs changed.

Beth shared a photo of a cluttered desk to represent her own carefully assembled information package, conveying busyness and hard work (Figure 4). Unlike Ann's metaphorical image, Beth's photo was literal, depicting the physical space where she sifted through large volumes of information. The image conveyed the scale of the task, with digital devices symbolizing the vast resources available. Beth explained how she had narrowed her search to several key services, yet still found that there was more information to uncover.

Beth: I'm gonna have to do all that groundwork by myself. (. . .). And I narrowed it down to 137. So now I will start looking at it closer and narrow it down a little bit more.

Beth, Ann, and Mummymoo all convey a lonely image of carers shaping the information they need by themselves without any help. They felt they lacked support from professionals. Beth thought practitioners would only help if she told them there was a crisis, whereas Mummymoo felt she

FIGURE 3: Participant-created photo representing an active process.

FIGURE 4: Participant-contributed image contextualised in narrative.

was not directed to the right places by agencies. Ann was left to make sense of a mountain of information herself.

8.1. An Information Bridge. However, despite the lonely figures cut by these participants' stories, many articulated that it was the other carers who provided the most useful information. This pattern is captured within the subtheme. Other studies have also highlighted that a key benefit of carer-centered group activities is the opportunity to share information. For example, Munn-Giddings and McVicar [16] suggest that carers often provide one another with more nuanced and practical information than professionals can, such as which local dentists offer home visits.

Esmeralda contrasted her frustrating signposting experience with receiving information from a carer she knew with substantial experiential knowledge and who realized the importance of providing information simply and easily.

> *Esmeralda: The most useful advice I've had (. . .) came from a friend who has been a carer for a long time, (. . .). The advice was given very succinctly, and it was followed up with links to "here's how to actually apply for these things," which I found really helpful.*

The most frequent form of support from other carers was in understanding and navigating the complexities of health and social care systems. For example, another carer told Meduck that he could alter a funding situation that was not working out. Jill, a member of a carer-led project, set out the way in which her project shared information with other carers.

> *Jill: Written simply, described simply, explained simply, was absolutely key (. . .). All the bureaucratic information (. . .) out there, translated very simply.*

Sam, another member of a carer-led project, understood that carers received information differently, depending on their preferences, abilities and learning style. She depicted this through a photo showing how carers could travel down different pathways to get the information they wanted in ways that worked best for them (Figure 5).

> *Sam: There are so many routes that you can take (. . .) and some routes can be longer and a rougher terrain (. . .) than others. (. . .) There are different ways of getting to the point that you need to be at. (. . .). So, it's just being able to share those different options and some of them will suit some people and some will not.*

Knowing that information and help came from experienced carers enabled a unique trusting bond to develop among carers. Brenda, for instance, found that a carer-led project supported her with a complaint when no other professional helped her.

> *Brenda: This (carer-led organization) helped me make a complaint against him. And that took a lot of time and effort. I got a lot of support from (carer-led organization) to help me do that.*

Participants described other carers as giving them information with empathy and kindness, the shared commonality causing both parties to feel emotionally invested. Sam described how receiving information from another knowledgeable carer had a relaxing effect on her (Figure 6).

> *Sam: It actually makes me feel more relaxed. (. . .) this person (. . .) gives me information which can make my shoulders drop a little and it's reassuring. And because I respect this person's knowledge and skills and experience, I am all ears to listening to solutions.*

The photo she chose to depict such feelings demonstrated how carers could impact on others in a positive, emotional way through their knowledge and empathic delivery of information.

However, some participants told of how other carers may inadvertently repeat inaccuracies within mutually supportive spaces, and these could then be very difficult to correct or disentangle. Jill described her position as an onlooker in a carer-led space, aware that information being shared was inaccurate but not being able to correct it (Figure 7).

FIGURE 5: Image created by participant to explore information-sharing.

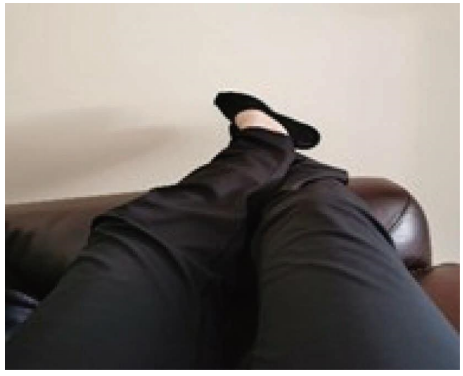

FIGURE 6: Participant-generated photograph linked to participant reflection.

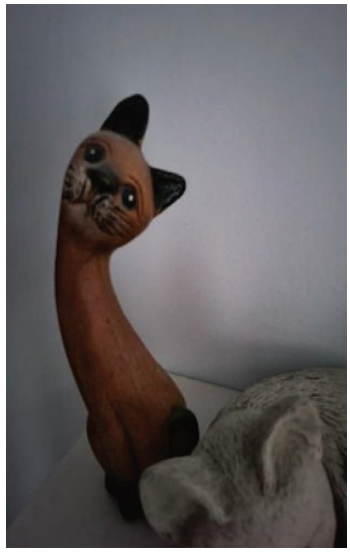

FIGURE 7: Photovoice image submitted by participants to convey meaning.

Jill: I'm the cat that's on the far left with my very long windy neck with a face that's very interested. Keen. Curious. But, somehow, also bemused. (. . .). Some carers were mis-interpreting the law, and I don't blame them for that. But I was able to understand that that has a knock-on effect if other carers are picking up wrong information.

Sam too was aware that information shared among carers was not always reliable.

Sam: Sometimes I've fallen foul of taking on advice, and then it just not materializing.

The article's main theme, "information highway: a sculptured journey," centers on the overwhelming nature of information encountered by participants, who described being inundated with information that was hard to navigate or apply in practice. In response, some participants described building their own tailored systems to filter and organize what they needed. The subtheme, an information bridge, illuminated how participants felt more confident when accessible information was shared with them by other carers, often within carer-centered group activities. These exchanges were shaped by common experience and emotional trust, allowing for timely and relevant support that differed from formal provision. Although these informal methods often proved more helpful than official sources, participants also acknowledged limitations when complex inaccuracies went unchallenged. Nonetheless, their value in providing timely, trusted, and emotionally resonant information suggests that carer-led information sharing may hold underrecognized potential in meeting the Care Act's legal duties in practice.

9. Discussion

The analysis suggested that carers often take the lead in identifying and sharing useful information, particularly when navigating fragmented systems. Rather than passive recipients, they were positioned as active interpreters and curators of knowledge, a point echoed by Munn-Giddings and McVicar [16], who emphasize the value of carer-led insight.

In keeping with the study's aim, the analysis considered how carers shared and interpreted information within community spaces, and how this may support the Care Act's information and advice duties in practice. This study has illustrated that carers' own practices of information sharing often address gaps left by current interpretations of the Care Act's information and advice duties. The common practice of signposting does not correspond with the statutory guidance for the Care Act [8] which contains lots of complex examples, nor with what carers need, which is often to understand and navigate complex systems on behalf of themselves and loved ones. Other carers can give reassurance, emotional support, and the benefit of experiential knowledge.

Yet, the possibility of inaccurate advice being shared in the face of these complexities highlights the value of facilitated support during carer-centered group activities. It was important to participants to be in spaces that were carer-led, rather than professionally run, while, at the same time, receiving easy-to-understand, accurate and accessible information. One way of achieving the balance between all these needs is for the exchange of information within carer-centered group activities to be facilitated, either by an experienced carer or a practitioner, while ensuring the shared experiences of carers remain prioritized during the sessions. This would enable carers to feel their voice is heard, while, at the same time, skilled facilitation would support the accuracy of information shared. One way forward would be to use community social work or community development skills to achieve this balance [14, 27]. In a community social work approach, practitioners might focus on fostering an environment where carers feel enabled to share their experiences and access accurate information in ways that resonate with them within an atmosphere of trust and empathy. Rather than leading, a community social work practitioner would support the space by ensuring resources are available and accessible, subtly guiding only as needed to maintain accuracy while preserving the autonomy and mutual support foundational to carer-centered group activities. Further research could examine how carer-centered group activities, supported by community social work skills, might extend or complement how the Care Act's information and advice duties are understood and implemented in practice.

The analysis suggests several implications for community practice and policy. First, carer-centered group activities require sufficient resourcing and recognition if they are to support carers in navigating complex systems. Second, practitioners working in community contexts may benefit from recognizing how emotional safety, shared knowledge, and mutual trust operate within these spaces. Finally, future policy implementation could build on these insights by developing local strategies that extend beyond signposting and formally recognize the value of relational, informal spaces in supporting information and advice duties.

10. Conclusion

This article has explored the ways in which information sharing is important to, and workable for, carers, particularly in the context of the Care Act's legal duties. Although this duty is specific to England, carers in other contexts may also face challenges accessing timely and meaningful information. It has been suggested that carers often provide the most helpful information and support, not only because of their knowledge but because they share it with kindness and empathy, supporting others who are navigating complex systems. However, the inability to challenge inaccuracies or misinterpretations within fully autonomous carer-led activities suggests that gentle facilitation may sometimes be helpful, provided it supports rather than displaces carer-led knowledge.

Ultimately, this study draws attention to the invaluable role that unpaid carers play in supporting one another through information sharing. When this happens in a carer-led environment, trust and mutual understanding can flourish.

Data Availability Statement

Data sharing is not applicable to this article due to the sensitive and confidential nature of the qualitative data generated.

Conflicts of Interest

The author declares no conflicts of interest.

Funding

No funding was received for this research.

Supporting Information

Additional supporting information can be found online in the Supporting Information section. *(Supporting Information)*

Title: Analytic Snapshot, Theme Development, and Quality Considerations.

Description: This file contains the following:

- A detailed account of the analytic process using the six phases of reflexive thematic analysis [17].
- Detailed theme development as applied in this article.
- A reflection on quality and alignment with Braun and Clarke's [25] guidance.
- A worked coding extract from NVivo (Phases 1-2).
- The photovoice question used to generate the data explored in this article.

See Supporting Information for further details on the analytic approach and process.

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