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A qualitative exploration of the barriers and enablers to supporting informal and familial carers within community pharmacies

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Abstract

Objectives: There are approximately 5.3 million informal carers in the United Kingdom, many of whom support family in their health despite being unpaid and often unsupported. Many visit pharmacies to collect medicines and look for advice. This work explores informal carer support within community pharmacies (CP).

Methods: Semi-structured video interviews exploring perspectives on the role of CP in supporting carers were conducted in autumn 2022. The study received institutional ethical approval. Interviews were audio-recorded, transcribed verbatim, and analysed using a reflexive thematic approach.

Key findings: In total 25 interviews were conducted with 13 carers and 12 pharmacy staff. Three themes were identified:

-What support do carers need through CP?—medicines management, navigating services, and carers health and wellbeing.

-Barriers to CP better supporting carers—relationships with CP, carer needs, identification as a 'carer'.

-Enablers to CP better supporting carers—support is a team effort, and CP as a community 'hub'.

Conclusions: There is a trusted relationships between carers and pharmacy staff which can contribute to establishing pharmacies as a safe space of support, this includes medicines-specific support and navigating services, but also carer health and wellbeing support. Pharmacy staff may need to reconsider approaches to identifying and supporting carers and not just treating them as an extension of supporting a patient. In making this support accessible, relationships with pharmacy staff are important, as well as embracing CP as a 'community hub', although pharmacy staff may need training and information to facilitate them in this role.

Keywords: caregivers; pharmacies; pharmaceutical services; pharmacists and community pharmacy services

Introduction

There are approximately 5.3 million informal carers in the United Kingdom, and this is likely to increase due to an ageing population [1, 2]. An informal carer is defined as '*anyone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid*' [3]. It should be noted that the term informal carer can be misrepresentative as it can minimize the importance and impact of the role [4]. Despite this, it is the most used term and 'carer' has been adopted here to refer to informal, unpaid carers as opposed to formal, paid carers.

Most often, carers provide care to a family member, such as caring for a spouse or adult children providing support to parents [1]. The type of care provided can vary but includes: help with everyday tasks such as getting out of bed and personal care; support with medicines management and administration; and emotional support such as helping someone understand their diagnosis [5]. The health and wellbeing of patients and their carers are inextricably linked meaning if we look after one we look after the other due to their interconnectivity [6]. Poor outcomes for the patient can lead to a substantial health and wellbeing risk to the carer, who may themselves go on to need care and *vice versa* [7, 8].

Considering medicines management activities, Sawan *et al*. explored carer experiences in medicines use, describing areas of carer concern: inadequate information about medication management; limited engagement in decisions; and difficulties with medication supply [9]. Many carers regularly visit pharmacies to collect medicines and they have established relationships with staff and so pharmacies are seen as accessible places to get advice, which can contribute to easing carer burden [10, 11].

Despite this, a majority of carers feel that signposting from healthcare professionals is limited and that support is more likely from charities and carer organizations [3]. Signposting through pharmacies tends to be ad-hoc and carer-driven linking carers with mental health services and social care [12, 13]. One of the reasons for this is that healthcare professionals

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can struggle to identify carers; this is recognized by the carers themselves who feel unseen [14, 15]. Better prepared pharmacy staff could help carers to recognize the significance of caring as they themselves sometimes do not appreciate this whilst in a caring role [16].

Much of the work to date has focussed on describing and evaluating the effectiveness of the carer role in improving patient outcomes [17, 18], particularly in medicines management [10, 18, 19]. Less focus has been on the interaction and roles of community pharmacy staff in supporting carers themselves.

Aim

To explore perspectives on informal carer support within community pharmacies.

Objectives:

1. Understand the nature of support needed by carers which could be delivered through community pharmacies from the perspectives of carers and pharmacy staff.
2. Understand the barriers and enablers to how carers can be better supported in community pharmacies from the perspectives of carers and pharmacy staff.

Methods

Methodology

A reflexive thematic approach as defined by Braun and Clarke was used with a constructivist methodology to understand meaning through the experiences of individuals in particular contexts [20]. The consolidated criteria for reporting qualitative studies (COREQ) were used (see Supplementary Materials). The project received ethical approval from the Faculty of Medical Sciences ethics committee (References: 25925/2022; 25368/2022).

Research team

A qualitative approach emphasizes researchers' involvement in interpreting data, therefore understanding the research team is important [20]. CR is an academic pharmacist and LL is an academic psychologist and qualitative researcher. J.L. and K.E. are pharmacy students who undertook data collection and initial analysis.

Sampling and recruitment

To be eligible to take part in the study participants had to either be:

- Pharmacy staff working in a UK community pharmacy. This includes registered pharmacy professionals and unregistered pharmacy staff such as pharmacy dispensers.
- Aged 18 years and above with lived experience as an informal carer accessing community pharmacy services and based in the United Kingdom.

Participants were free to withdraw from the study at any time and no prior relationship existed between the researcher and participants. Convenience sampling was used through professional networks, social media, and a public involvement organization (VOICE-global.org).

Data collection

In depth, semi-structured video interviews with carers and pharmacy staff were conducted via Microsoft Teams or Zoom. The interviews explored the feelings and perspectives of participants on carer involvement in community pharmacy. Questions were based on the author's understanding of relevant literature [10, 18, 21, 22]. Participants required an electronic device to participate in the interview. Interviews continued until the information power of the data was sufficient, determined via author consensus that further interviews did not produce new information [23].

Data analysis

Reflexive thematic analysis was used to analyse the data inductively [20]. Interviews were conducted by J.L. and K.E. and were transcribed verbatim using automatic transcription technology. The transcripts were reviewed for accuracy by J.L./K.E. and C.R. C.R. inductively coded the data in discussion with authors. Descriptive codes were grouped and discussed becoming emergent themes, and then final themes.

Trustworthiness was considered via providing a 'thick' description of the participants' perspectives to facilitate reader judgement of the transferability of the work, in keeping with a thematic reflexive approach [20]. Negative case analysis was used to search out and analyse deviant cases [24].

Results

Overview

A total of 25 interviews were conducted with 13 carers and 12 pharmacy staff; length varied from 23 to 67 min (mean 34 min). Each participant was given a code based on their role and order of interview (Table 1).

Thematic analysis

From the thematic analysis, three themes and several subthemes were identified as described below (Figure 1.).

What support do carers need through community pharmacy?

Carers and community pharmacy staff described various aspects of support that carers may need in which community pharmacy could contribute to. These fell into three groups: medicines management, navigating services, and carers own health and wellbeing needs.

The carers described having to learn to know how to be a carer. Firstly, for carers this included needing to know about medicines management, especially personal methods tailored to individual patients and learning explicit knowledge around the safe use of medicine e.g. what they are for and if they have to be taken regularly.

> *"I learned over time that some of [the medicines], you do have to take every day like the warfarin, but if you miss the Panadol or the simvastatin every so often, then it's no big deal."* [C3]

> *"I've developed a technique if you like, if we're going to give her porridge in the morning. especially whenever she was taking the steroids following the chemotherapy… so I used to pile them in to the porridge."* [C10]

Table 1. Demographics of interview participants.

Participant code	Role	Gender	Person cared for	Other information
1C	Carer	Female	Father-in-Law	
2C	Carer	Male	Neighbour	Volunteer carer advocate
3C	Carer	Male	Parent	
4C	Carer	Male	Parent	
5C	Carer	Female	Sibling	
6C	Carer	Male	Parent	
7C	Carer	Male	Parent	
8C	Carer	Female	Parent	Healthcare professional
9C	Carer	Female	Parent	Healthcare professional
10C	Carer	Female	Parent	Healthcare professional
11C	Carer	Female	Parent	
12C	Carer	Male	Spouse	
13C	Carer	Male	Father and Mother-in-law	Employed as a carer advocate
1P	Pharmacist	Female		Lived carer experience
2P	Trainee pharmacist	Female		
3P	Trainee pharmacist	Female		
4P	Counter assistant	Female		
5P	Trainee pharmacist	Female		
6P	Trainee Pharmacist	Female		
7P	Counter assistant	Female		Lived carer experience
8P	Pharmacist	Female		
9P	Pharmacist	Male		
10P	Trainee pharmacist	Female		
11P	Trainee Pharmacist	Male		
12P	Pharmacist	Male		

Trainee pharmacist refers to both undergraduate pharmacy student and pre-registration trainee pharmacists.

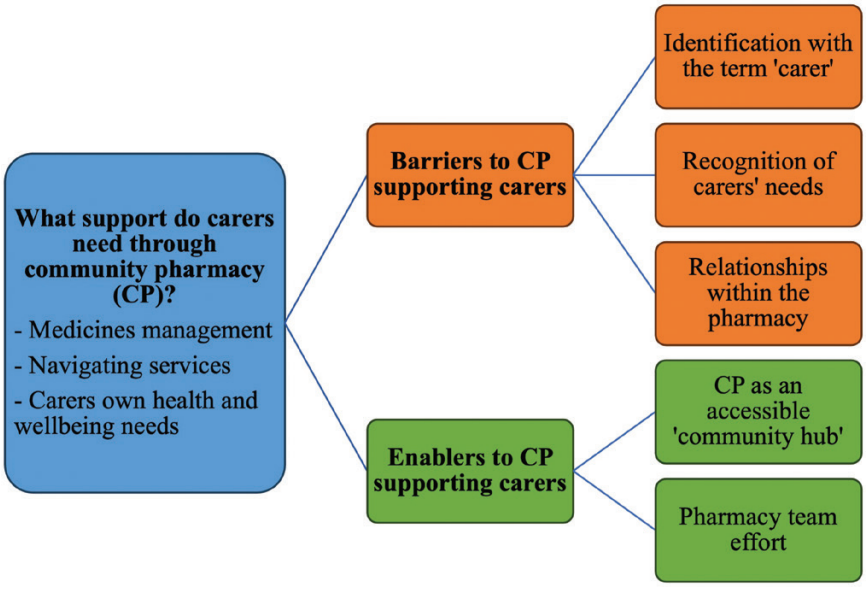

Figure 1. Concept map of the study themes and sub themes.

Commonly, carers reported they had limited understanding of medicine related matters prior to becoming a carer. And once in that role, they were left to teach themselves in order to know what medicines their family member was taking.

> *"I teach myself so I kind of have a rough idea of what medications are involved."* [C3]

Carers described a feeling of being marooned when learning medicine management. They did not receive structured

support from pharmacies in this area other than *ad-hoc* carer-driven support.

> *"And because my number is now on the system, they know that they can ring me because I left my number, I mean it was myself. It wasn't something that was asked."* [C13]

Secondly carers, described having to learn how to navigate systems and processes around accessing medicines services. They perceived this was as an additional barrier they faced.

> *"[you have to] learn how the system works in order to get help from it. It should be almost intuitive…how [the health and social care system] works."* [C2]
>
> *"So there has been some hiccups with that in terms of understanding between me, the pharmacy and the practice and the pharmacy and the practice. But eventually we've got them ironed out now, so we know, that we have to e-mail the practice with the prescription or with whatever medications we need, they send it to the pharmacy and the pharmacy either delivers or we go and pick it up."* [C10]

Some carers discovered wider health and social care benefits they could make use of due to their caring role. These were often discovered by chance as the system was perceived to be unclear.

> *"Yes, if you knew what allowances were available, what additional support was available? So, for example, when we were in hospital, the hospital social worker said to me. Ohh, you know, you should get a carers assessment done by the social worker cause there's lots of support available to you and I'm thinking really? nobody told us. So most definitely, yeah, just to know that there is additional support out there that you can tap into."* [C10]

A further area where carers described a lack of support was around their own health and wellbeing and how this was being impacted by their caring role.

> *"I think my mom's on antidepressants because the situation [caring responsibilities for husband]. My brother [a further carer] stopped leaving the house. It's been two years, and he doesn't really go out anymore. And I've only just been discharged from therapy... So, pretty massive effect" [C7]*

Equally, professionals recognized that caring can come with an emotional burden.

> *"emotional burden is really important, because [carers] are not prepared often for the situation [carers] find themselves in, but they've got no control over being in that situation..."* [P1]

However, pharmacy staff had mixed understanding of this emotional burden contributing to a risk of deterioration in carer health and wellbeing. This was demonstrated by one participant who showed some awareness of carers having health needs, but linking this more to pre-existing carer illness rather than the person's health and wellbeing being directly influenced by caring.

> *"we've had quite a few [patients] where sometimes the carers aren't well either. So, it's kind of like you've got a couple where both of them are unwell."* [P4]

Barriers to CP better supporting carers

Carers and pharmacy staff described several barriers to better carer support within pharmacies. The three key areas were: relationships with the pharmacy, recognition of carer needs, self-identification with the term 'carer'.

Meaningful relationships between pharmacy staff and carers were important to carer experience, particularly feeling like an individual whom staff got to know. This was perceived to be more typical in smaller or independent pharmacies.

> *"there was a long-term relationship built up with [pharmacy staff]. They got to know me and the other important thing about the pharmacy is they had a regular had staff that have been there for years."* [C6]

Conversely, pharmacy staff recognized the support of carers is more difficult when there are locums or non-regular staff who do not have the time to build relationships.

> *"there's locums…they don't know all the patients as individuals."*[P4]

Carers described a perception that support was only provided to enable better care for the cared person rather than to look after them. There was a desire also to be recognized as a patient with their own health and wellbeing needs.

> *"I think there needs to be a lot more support. When [the help was] escalated that was to avoid the home situation breaking down rather than really, I feel, caring for me."* [C8]

The perception of the carer being secondary, was supported by some pharmacy staff who described supporting the carer as a way of better supporting a patient rather than carers needing support for their own health and wellbeing.

> *"it's helping to support the carer, to then support the patient. It's kind of, so that everything can run smoothly and again, like making sure the patient is the priority. If we can support the carers, then that better supports the patients which would mean that they might either get better or they don't need to go back to the doctors as often."* [P4]

A contributing factor to unsupportive carer experience in the pharmacy could be due to confusion over terminology and recognition of carers. For carers this appeared to stem from a lack of resonance with the term carer as they had found themselves in the role as an expectation due to an existing familial relationship.

> *"not that you've been forced it to it, but it's an expectation that you know you look after your parents"* [C11]

As a consequence of the perceived cultural expectations to become a carer, carers appeared to struggle with identifying themselves as a carer.

> *"I just do it a lot of the time and I don't see it, as you know, I'm a carer with that kind of label."* [C10]

This was equally supported by pharmacy staff who recognized similar issue of carer identification due to a perception that it is a 'formal' role.

"whether [carers] perceive themselves to be carers or not is slightly different. Because I think they think it's something that's more formalised, whereas really a definition of a carer isn't the formality, it's the person that's helping." [P1]

Enablers to CP better supporting carers

Two enablers to pharmacy being able to better provide support for carers were described: pharmacy team effort, and community pharmacy as an accessible community 'hub'.

Participants were positive towards the accessibility of community pharmacy and community pharmacy staff in terms of availability and being able to speak to staff.

"I think the fact that community pharmacies are so open, and like, there's always an availability to come and speak to a health care professional" [P4]

This contrasted with pharmacy staff who perceived staffing and any long wait times to contribute to more negative experiences.

"where I work is like pretty under-staffed. Um, so there's always like a queue. It's always really busy, you know, like people get a bit frustrated…" [P3]

However, by both groups of participants, carer support was recognized as a collective effort by the team and not only the responsibility of the pharmacist.

"It doesn't have to be the pharmacist… someone else could talk to the carers... I think if you could educate technicians..." [P4]

Because of the perceived accessibility and being located in community setting, carers recognized that pharmacies are not just a place for medicines supply but increasingly a space for wider services with one participant describing a pharmacy as a 'community hub'.

"It's about knowing what services are available at your pharmacy and what's support there, and it's not just about going in there and collecting your medication and that's it… I think it's also it's like it's become like a bit of a community hub..." [C11]

Pharmacy staff did not necessarily recognize this themselves. Their focus was more on medicines specific services but they recognized that carers were navigating an unknown system of knowledge and services.

"It's actually understanding where the right places are to go and also then add in things maybe like a language barrier, but also don't forget the way we talk as professionals, medical jargon, etc. [carers] won't know that… it's more about service design and delivery as a barrier." [P1]

Pharmacy staff did not overtly discuss pharmacies as a potential place to deliver carer support wider than medicines management.

"So we could signpost that's absolutely right. And because, the thing that was interesting was the people from the charity were saying, people don't know we exist. So actually they're running this really good thing, but the barrier to it is actually no one's passing the information on. So I, so yes, it was more of a sign posting thing and that's the only thing I've ever had." [P1]

Discussion

Carers and pharmacy staff recognized that carers may need support which could be provided through CP, this included medicines-specific support and support for carers in their health and wellbeing. Carers described a cultural expectation of caring as part of existing relationships with their family member. This caused problems with identification of the role as 'carer' within pharmacies, and contributed to the emotional burden of caring.

Carers reported that caring negatively contributed to their health and wellbeing and at times they felt unseen as patients. Both pharmacy staff and carers reported that a long-standing relationship with the pharmacy made supporting carers easier, yet pharmacy staff described they struggled to perceive carers as individuals with their own health and wellbeing needs but rather as a means to facilitate better patient care. This is supported by literature within dementia where it is acknowledged that carers require support for their own health and wellbeing or risk becoming 'secondary patients' [25].

CP offered carers a place for support as a 'community hub'. The significance of the pharmacy as a community space was not always acknowledged by pharmacy staff who were more concerned around wait-times and staffing. Increasingly, pharmacies are recognized to offer services past medicines use, around wider health and wellbeing [11, 26]. In 2013, one study acknowledged the need to overcome professional barriers before pharmacies could become health hubs. The results of this study would support that is still the case a decade later [26].

Trusted relationships between carers and pharmacy staff can contribute to pharmacies being seen as a safe healthcare space [27]; but pharmacy staff may need further training to support carers effectively [28]. A starting point may be better carer identification within pharmacies, which has been limited within primary care previously [29], it is noted that pharmacy staff need further training and information to facilitate them in identifying and then supporting carers [13]. A priority would be increasing awareness of pharmacy staff that carers themselves struggle to identify themselves as carers and may be disregarding their own health and wellbeing [30]. This could be achieved through training packages and awareness campaigns about who carers are and what support they may need. As a result, offering support may need to be proactive rather than reactive [29].

Carers learning how to navigate health and social care systems is similar to a hidden curriculum which is the theory that for a learner (a carer) to succeed within an education system (navigating their role and the health system) they must not only learn the formal rules and knowledge (medicines-specific information), but also the informal rules, beliefs and attitudes perpetuated through the socialization process (the systems and processes of services) [31]. This learning process for carers in terms of both medicines-specific knowledge and service understanding, can be complex for carers and this can contribute to carer burden and, deterioration in health and wellbeing [7, 8, 32].

The work of Latter et al., concluded face-to-face educational interventions have the potential to improve carers' knowledge about pain management [33]. However, this study did not consider a connection between educational interventions as a method of improving carer knowledge and thus their ability to care, and improvements in carer health and wellbeing as an indirect outcome, but our study suggests this relationship may warrant further investigation. This is particularly pertinent given our study reports that identification with the term 'carer' possibly due to cultural or familial expectations to care, coupled with navigating a 'hidden curriculum' of caring to be barriers to carers receiving support in pharmacies yet if these are overcome and pharmacies enable better carer support this could contribute to easing carer burden and supporting their health and wellbeing.

Implications

Pharmacy staff currently appear to rely on ad-hoc signposting rather than meaningful and holistic carer engagement, particularly due to difficulties identifying carers. Future work could consider identification and support of different carers within pharmacies and the role of the pharmacy team within this as part of a community hub. Considerations as to the interconnected relationship and resulting provision of services between patient, carer and pharmacy staff may require further research.

Limitations

This paper used a varied sample of carers and pharmacy staff, however due to the heterogeneity present within both of these groups it is possible some views are not represented. One example being the years of experience of pharmacy staff and also that ethnicity was not recorded as part of this work which require further investigation. This is particularly for carers as there are recognized differences between ethnicities as to the culture around caring [34, 35].

Conclusion

Being a carer can be a cultural expectation and also a contributor to worsening carer health and wellbeing. This is made more challenging by the need to learn and navigate a complex, hidden curriculum about services and medicines. Community pharmacy can offer a place for support, but pharmacy staff may need to reconsider their approach to identifying and supporting carers in their own right and not as an extension of supporting a patient to receive better care.

Supplementary Material

Supplementary data are available at *International journal of Pharmacy Practice* online.

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Conflict of interest

The author(s) declare that there are no conflicts of interest.

Authorship statement

All authors planned and designed this study with K.E. and J.L. conducting the interviews. All authors were involved in the analysis and interpretation of the data and the drafting of this manuscript.

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Data availability

Authors collected and had access to all data throughout the study. The data underlying this article will be shared on reasonable request to the corresponding author.

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