



The Role of the Community Pharmacist in Breast Cancer Services

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This final report presents research funded by Pharmacy Research UK (PRUK reference number: PRUK-2017-PA4-A). The views expressed in this report are those of the author/s and not necessarily that of Pharmacy Research UK.

Abstract

Background

Breast cancer is the most common cancer in England, but survival rates are improving. Survivors often require long-term medication to prevent breast cancer recurrence and report insufficient post-treatment care. Increasing demand for breast cancer-focused services in the community setting has created potential scope for community pharmacy to take on a larger role.

Research Question

What are the opportunities for community pharmacists to develop their role in providing support and improving health outcomes for people living with and after breast cancer?

Methods

A 3-phased approach explored the perspectives of breast cancer survivors, community pharmacists and stakeholders respectively. Phase one consisted of focus groups and interviews with female survivors, investigating experiences of the breast cancer care received in the community and identifying areas where community pharmacists might have scope to support. Community pharmacist focus groups were then conducted online using instant messaging to explore attitudes, feasibility and operational aspects of introducing a pharmacy-led service or intervention. Finally, stakeholder interviews established perspectives on findings, along with suggestions for future work. Survivor and stakeholder data were digitally audio recorded whilst typed transcripts from the community pharmacist focus groups were downloaded. All data were analysed using iterative thematic analysis.

Results

Survivors reported initial information overload then feeling abandoned post-discharge, a lack of information and support, being unsure where to seek care, and struggling with medicines-related problems and emotional burdens. They felt that early contact with community pharmacists would improve their experience and welcomed the idea of personalised and holistic care. Community pharmacists and stakeholders noted the importance of providing the right information at the right time. Strategies included appropriate signposting, collaborating with other healthcare providers and charities, tackling public perceptions of roles, and building pharmacist confidence. Potentially feasible interventions included incorporating breast cancer into existing advanced services and healthy living pharmacy campaigns.

Conclusions and recommendations

This study identifies considerable scope for community pharmacists to take on a larger role in breast cancer survivorship services, highlighting several potential features of future interventions. Increased awareness of survivor care needs amongst community pharmacists is needed to encourage proactive conversations, networking activities and further training. Findings can inform the development of community pharmacy survivorship services and healthcare policy. Future research should further investigate the feasibility of proposed interventions; considering how they could be incorporated into the changing landscape of pharmacy services.

Background

Breast cancer is the most common cancer in England and due to earlier diagnosis and advances in treatment, survival rates have been continually improving.^{1,2} Breast cancer survivors are often required to take long term medication to prevent recurrence, such as a five-year course of endocrine therapy (ET)³. Due to the increasing need for more long-term care, primary care is now being recognised for its developing roles in supporting people throughout their cancer journey and helping them adapt to the many psychological and physical challenges of life with and beyond cancer⁴. Within this, there is particular scope for improved primary care services during the post-active care stage of the cancer journey, and the need for improved survivorship services has been acknowledged.⁵

Cancer survivorship can be defined as: “the health and life of a person with cancer post-treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases”⁶. This study will focus on the treatment and support provided for breast cancer patients in primary care. The term ‘survivor’ will, therefore, be used to describe patients that have been discharged from hospital following their initial treatment for breast cancer, and hence are being managed within the community.

Community pharmacists are widely regarded as the most accessible healthcare provider in primary care⁷ and their potential to support in the prevention and management of cancer in general has been recognised. Pharmacists are well-placed for example, to promote healthy living – both in terms of cancer prevention and survivorship care. As experts in medicines optimisation, they could also have a role in optimising cancer treatments and managing side effects or late effects.¹

Despite the acknowledged scope for community pharmacy to support cancer survivors, little progress has been made to date in increasing survivorship support within this setting. Although not aimed exclusively at survivors, one notable source of support is the Boots Macmillan Information Pharmacist (BMIP) role; developed through a collaboration between Macmillan Cancer Support and Boots UK. The BMIP training has been completed by Boots pharmacists across the country; equipping them to provide advice and some emotional support to survivors (and their friends or relatives); as well as signposting to additional services as required.⁸

In addition to the demand for survivorship services overall, the long-term care requirements for breast cancer in particular have created opportunity for community pharmacy to take on a larger role, providing scope for a pharmacist-led intervention to deliver better support, optimised treatment and improved health outcomes for survivors¹.

Research Question

What are the opportunities for community pharmacists to develop their role in providing support and improving health outcomes for people living with and after breast cancer?

The objectives of the study were to explore the healthcare needs, attitudes and opinions of breast cancer survivors towards new community pharmacy-based cancer services and identify points in the breast cancer journey where community pharmacists could support patients to improve their outcomes and quality of life; to investigate pharmacist views on introducing a service or intervention to meet these care needs, exploring potential opportunities and barriers surrounding implementation within the community pharmacy setting; and finally, to establish the views of relevant stakeholders towards the introduction of a new community pharmacy-based service for breast cancer survivors, including next steps and future work.

Methods

Study Design

This study, which forms part of a mixed methods project, utilised qualitative methods as part of a 3-phased approach to explore the perspectives of breast cancer survivors, community pharmacists and stakeholders, respectively. The findings from each phase were used to inform the design of subsequent phases.

Semi-structured focus groups were selected as the most appropriate means of obtaining the required qualitative data since they often produce richer data than individual interviews. The natural conversational context is conducive to exploring participants' experiences and perspectives as well as supporting the generation of ideas; making this a commonly adopted within health services and pharmacy research.⁹⁻¹¹

During the initial phase, focus groups and interviews explored survivors' experiences and views of the breast cancer care received in the community. Participants considered how community pharmacists might address any unmet care needs and better support survivors. Findings were then followed up in pharmacist focus groups to explore attitudes, feasibility and operational aspects of introducing a pharmacy-led service or intervention. Finally, individual interviews with relevant stakeholders were conducted considering their perspectives on findings, as well as suggestions for future work.

Prior to data collection, a Patient and Public Involvement (PPI) activity was carried out. This involved a preliminary interview with a breast cancer survivor to identify key themes for discussion to supplement the interview schedules (Appendix 1). The participant was purposively selected to act as an 'expert patient' based on her survivor status and her background in pharmacy practice research; enabling her to provide unique and valuable insights into the issues faced by breast cancer survivors whilst helping inform the development of the data collection tools from a research perspective (Appendix 2).

Sampling and recruitment

Three geographical regions were selected within which to conduct the survivor focus groups. Including survivors from more than one location aimed to account for possible differences in care provided across different areas, increasing the overall representativeness of the findings. South Warwickshire, Lincolnshire and Nottinghamshire were purposively sampled due to both their adjacency and their high numbers of pharmacists with an active interest in improving cancer services; this was expected to maximise recruitment opportunities.

Survivors were recruited through community pharmacies, which were approached to display recruitment posters and flyers (Appendix 3). These pharmacies initially identified through existing professional contacts and snowballing. Survivor participants either volunteered after seeing recruitment literature, or were opportunistically invited to participate through the BMIP service. In order to be eligible for inclusion, the survivors were required to meet specific criteria (Appendix 4).

Both the community pharmacist and stakeholder participants were recruited from across England to maximise recruitment opportunity and representativeness. Participants were purposively sampled and recruited through existing professional contacts and snowballing. The inclusion and exclusion criteria are detailed in Appendix 4.

Data collection

The survivor focus groups were conducted on a face-to-face basis. For those who could not attend, an individual interview was conducted; either face-to-face or over the telephone, according to the participants' requirements. All survivor focus groups and interviews were digitally audio-recorded and transcribed verbatim.

Since community pharmacists were recruited nationally, a face-to-face approach was not reasonably practicable and focus groups were instead conducted online; using Skype for Business software. For

technical reasons, focus groups were conducted using the webchat feature; with the facilitator and participants each contributing to the discussion through typed messages. Following completion of each focus group, a copy of the full conversation transcript was made for data analysis purposes.

Due to scheduling and locations, a stakeholder focus group was not feasible. Individual interviews were instead conducted (face-to-face or over the telephone according to participants' requirements) and were digitally audio-recorded.

Data analysis

All data was analysed using iterative thematic analysis, using NVivo 11 software to facilitate the coding and organisation of data. This involved a cyclical process of reviewing and recoding data with each emergent theme. Using the developed codebook of themes, a second researcher then coded and compared one third of the data to confirm agreement with initial analyses.

Results

Survivor perspectives

In total, 13 survivors participated in the study. Three focus groups were conducted (one in each of the selected regions; involving 5, 3 and 2 participants respectively) and three individual interviews. Two overarching themes emerged from the data; *Concerns and barriers to care* and *Suggestions for improving care*.

Concerns and barriers to care

The most commonly occurring theme was emotional burdens. The breast cancer journey - from diagnosis, throughout treatment and recovery - is challenging and survivors felt that emotional support was not readily available. Emotional support meant different things to survivors; whilst some felt they needed formal counselling or treatment, others simply needed a friendly face to provide reassurance. Causes of emotional burdens ranged from fears about the disease itself and treatment, to practical issues such as financial concerns. Survivors were concerned not only about the emotional burden on themselves, but also on their friends, family and particularly young children.

"It's not just pills, potions that you need, its psychological help, you know. And to point you in directions of help so that you don't...I mean you're in this big hole and you're trying to get yourself out and you can't."

-Survivor_11

Medicines-related problems (defined as *"an event or circumstance involving pharmacotherapy that actually or potentially interferes with a desired health outcome"*¹²) were a common concern amongst survivors. Many took several different medications and often suffered side effects of their treatments (e.g.: surgery, chemotherapy, radiotherapy, endocrine therapy) and struggled to get information on minimising side effects or support managing them.

The lack of information provision was a big issue for survivors throughout their cancer journey; they often had no idea what their treatment plans involved, what to expect from procedures or treatments, what aftercare advice to follow, or didn't understand why they were prescribed particular medicines.

"Yeah the whole journey has been a lack of knowledge of services. You know the whole scene from being told this thing, and then you know, this is going to happen to you to the very end really, it's all you're being led by other people; medical people. And whatever they say I've followed like a little sheep and I've had it done. I haven't questioned anything anybody's ever said to me, you know 'you've got to have this' so I've had it. I didn't question why I was having it; 'why am I having these pills?' I just took them."

- Survivor_11

Survivors also experienced a lack of information provision in terms of sources of support available locally; such as charity events, support groups, exercise classes, sources of emotional support such as creative therapies or counselling services, or practical support such as returning to work. For those living in more rural locations, it appeared that such services did not exist locally, which often resulted in survivors having to travel long distances to access support.

“Anything I wanted I had to push to get. I had to pick it up and run with it, which is difficult if you’re not feeling on top of the world, if you’ve got cancer, I mean, even for a wig, I never did find out where the NHS wigs were; never did!”

- Survivor_05

Despite a general lack of information, most participants experienced an initial overload of information immediately following diagnosis. In contrast, survivors then reported feeling isolated after being discharged from hospital, and reported insufficient care and support in the community setting. This was an issue not only immediately after discharge, but also in the later years post-treatment when survivors suffered from concerns such as recurrence scares or late effects of treatment.

“You don’t have to come back for what, 3 months, 6 months? Well you come out - great, haven’t got to go back! You get home, you sit down and you think my comfort blanket’s gone! I’m on my own; there’s nothing.”

- Survivor_04

Throughout the treatment journey, there was a general feeling of being unsure where to seek care, and some reported being turned away by community healthcare providers (pharmacists, nurses, GPs) or being continuously signposted to other healthcare providers before eventually giving up. These experiences created a perception that community healthcare providers, unlike the specialists in the hospital setting, lacked the expertise to deal with cancer-related issues.

Lack of continuity of care was another concern. Over the course of their long-term treatment, survivors found themselves coming into contact with numerous different healthcare providers, each having no idea about their condition, treatment or history. Continuity of care seemed to be an issue not only between settings, but also within them.

“It’s like departments don’t talk to each other – there’s that one over there, there’s that one over there and you’re in the middle. It’s like the GP, the pharmacist, the consultant, the oncologist, the surgeon, and nobody talks”

- Survivor_05

In terms of community pharmacy, survivor perspectives were varied. Whilst participants were put off by how busy their local pharmacies were, they also appreciated the accessibility of community pharmacies and suggested that the development of new services could ease the workload of other NHS services. However, a key concern was the lack of privacy in the community pharmacy setting.

[Suggestions for improving care](#)

Survivors had many ideas on ways to improve care and attitudes towards the prospect of support services or interventions in the pharmacy setting were very positive. Some had already experienced excellent care from their local pharmacy throughout their cancer journey, and felt the expertise of pharmacists could be further utilised. Others who were perhaps less familiar with the potential role of pharmacists could see numerous advantages of additional support services, and appreciated the convenience of the setting. Being away from the hospital and with a less clinical feel, it didn’t carry the same negative connotations of ill-health for survivors. The accessibility of the local location and the potential lack of appointment system were also seen as huge advantages. Any service offered would need to be sufficiently promoted to encourage use and make busy pharmacists appear more approachable.

Survivor_08: *“Even just going through those hospital gates. It fills you with dread.”*

Survivor_07: *“Exactly. Even now there’s so much association. My local store, I don’t have that. So, to have that kind of community support, be it understanding what else is out there within the community, what groups where women can come and chat; because I never really did that. But it might be a few years down the line you want to do that. Would I go back to the hospital for that? No way. I only go there when I really need to! But community pharmacy, I wouldn’t feel like that about, so maybe there’s a space.”*

Many of the survivors were keen to be referred into their chosen community pharmacy by the hospital pharmacist or breast care nurse. Information sharing would improve continuity of care and equip pharmacists to deal with any queries from survivors and provide relevant advice on treatments and aftercare.

Survivors noted that as they progressed through their cancer journey, their needs changed over time; from initial information overload, to feeling abandoned post-discharge and the lack of support that continued into the later years. It was therefore important to personalise care around these considerations.

“I always think talking is helpful and it might not be that that time is the right time to talk, but later on you still might not have processed all your emotions and how you’re feeling about it and that might be more helpful later on.”

-Survivor_07

Building a good relationship with the community pharmacist early on in the journey was very important to survivors. Many commented that their experience would have been improved if they’d been aware earlier on about the roles and expertise of community pharmacists, and known they could support with long-term conditions as well as minor ailments. To support with early contact with the pharmacist, one of the focus groups suggested that pharmacies could offer an introductory pack, including information about the services offered in the pharmacy and recommended products. This could perhaps be obtained using a voucher provided by the hospital (similar to the bounty pack voucher system for expectant mothers), which the individual could then take to the community pharmacy; ensuring early contact.

Survivor_07: *“Even just a kind of list of things that you might want to get in because suddenly you’re getting a thermometer, when you didn’t have a thermometer, suddenly and you’re taking your temperature every day. Just a little pack of stuff that’s useful to have; buy it so you’ve got it in. If you feel in the middle of the night suddenly you’ve got this; your temperature’s up and whatever...”*

Survivor_06: *“A kit or something”*

Survivor_07: *“A kit of some sort and that then gives you that first point of entry with your pharmacist potentially.”*

The idea of a holistic approach to care was very popular and survivors felt that a regular consultation or check-up should be provided, during which the pharmacist could provide clinical advice on breast cancer and its treatments, such as medicines-related problems; but also consider general health and wellbeing needs, such as providing emotional support and advice on diet and exercises to manage side effects and aid recovery.

“If you did have that unsure niggle that you didn’t want to bother the GP with, it’d be that safety net almost that you could have somewhere else to go that wasn’t just that clinical ‘here’s your drug, are you alright with it?’ But it’s a bit more about the holistic care.”

- Survivor_07

Additionally, survivors felt they would benefit greatly from advice on safe and suitable products available for purchase in the pharmacy that could help them, given their condition, treatment and symptoms. Examples

of such products included suitable hair products to use on damaged or growing in hair post-chemotherapy, and products to strengthen damaged nails. Similarly, moisturisers, creams and other skincare products to soothe irritated and dry skin, or wound care for skin burned by radiotherapy treatment would also be very beneficial for survivors. Advice on suitable underarm products to use following surgery, such as deodorants, was also suggested.

“When I had my lymph nodes removed, you’ve got, it sounds really stupid, but you’ve got the problem of like, what can you use for hair removal? ...What deodorants do you use and things like that? That was really, really difficult.”

-Survivor_08

Community pharmacist perspectives

Two community pharmacist focus groups were conducted; involving four and five participants respectively. Between them, participants had a wide range of experience, from very rural settings to large cities and from independents to large multiples. After reflecting on survivor perspectives and considering feasibility, community pharmacists identified several opportunities for their profession to better support breast cancer survivors.

Survivor concerns surrounding information overload, post-discharge isolation, difficulties accessing care in the later years and lack of continuity of care led the participants to identify that pharmacists need to provide the right information and the right time.

Participants felt strongly that signposting more appropriately was a key opportunity to improve care for breast cancer survivors. They acknowledged that signposting to the GP is common practice; often because they themselves lacked knowledge about support available for breast cancer survivors. In order to deliver the more holistic service called for by survivors, appropriate signposting was recognised as being essential to ensuring care needs are met where pharmacists lack the resources or training to provide the required support themselves. In order to improve signposting practices, pharmacists felt that training on where to look for services, or a portal to collect information would be useful. On an individual level, they identified opportunities to collaborate and network locally; such as with their local hospice, Macmillan GP or Macmillan Information Manager to find out more about services within their local communities.

CP_02: “GPs again are not specialists in this area and probably, like us have limited knowledge - maybe multi-disciplinary face to face training so we learn together and develop wider networks”

CP_04: “That's something worth knowing because I will now avoid referring to the GP and consider alternatives - Macmillan Nurse? Be worth making contact with the local Macmillan GP?”

Community pharmacy was considered to be a good setting for survivorship services, but the importance of promoting community pharmacist roles to ensure survivors find them earlier in the journey would be essential. Additionally, advertising the availability of the consultation room and the services offered in the pharmacy was an important issue to tackle. Some of the pharmacists raised the issue that although they are Boots Macmillan Information Pharmacist-trained, there is nothing to distinguish them from pharmacists without the training; creating confusion amongst customers.

“I don't think that is limited to cancer care/advice/survivorship. there is a general lack of understanding and misconceptions about the pharmacist role and what we can do- I think it is due to the changing roles of pharmacists over the last decade or so. Hopefully with media campaigns and promotion of the profession this will change”

- CP_02

In terms of providing emotional support to survivors, views differed. One pharmacist felt her main role in supporting cancer survivors was to provide emotional support and another suggested that pharmacists could lead support groups. Conversely, others felt it was outside of their area of expertise and should be left to healthcare care providers with relevant training.

Pharmacists saw value in networking with local charities and healthcare services. Multidisciplinary training events with GPs and other healthcare providers were suggested to improve knowledge and promote working together. Collaborating with healthcare providers within and across settings was seen as essential to improving continuity of care. Sharing information on formularies and local services would be important to ensure that consistent messages are given by all healthcare providers.

Pharmacists were also keen to support survivors' in providing more information on safe pharmacy products to use during their treatment. Some already had experience of advising on such issues; having spent time calling manufacturers and the local hospital to establish which products to recommend. Pharmacists also acknowledged that some of the pharmacies situated within larger stores have beauty advisors who may also be able to support with this.

"we're in the position to give proper evidence based information where there is a lot of misinformation- cancer and deodorants, hair colours etc."

- CP_09

When considering the feasibility of potential interventions, the community pharmacists were enthusiastic about expanding their roles to provide improved care for breast cancer survivors and felt there was considerable scope for the profession to make a difference. However, they did have some concerns such as the lack of time to complete training and offer new services, as well as how a new service might be funded. Community pharmacists also reasoned that as their roles evolve; public perceptions of their expertise need to be updated accordingly in order to ensure sufficient uptake of new interventions or services. Some of the pharmacists felt that limiting interventions to support only those survivors with breast cancer would result in insufficient uptake to make the service worthwhile, and that cancer survivors in general should be included.

CP_06: "I think it is feasible and would be beneficial to patients to develop a new pharmacy service tailored to cancer survivors in general and not just breast cancer patients but whether or not it'll be funded is the real question especially in the current climate"

CP_05: "I agree with [CP_06]. If the service was widened to include all cancer survivors it could be offered in all pharmacies but if it were just for breast cancer survivors I'm not sure there would be enough patients to make it worthwhile to offer the service in every pharmacy."

A lack of confidence in providing advice on breast cancer was reported by the participants, along with the need for further training to accompany any future interventions or services. Subjects that pharmacists felt they needed more training on ranged from information about the condition, treatments and aftercare; to when to refer; to improving patient outcomes; to communication tips and advice on dealing with sensitive issues. The issue of information going out of date was raised, and an e-learning training pack similar to those offered by the Centre for Postgraduate Pharmacy Education (CPPE) was suggested that could be updated regularly. Pharmacists acknowledged that although they had a lot of requirements in terms of training, any information pack would need to be concise and limited to key information to encourage them to complete it. Additionally, pharmacists noted that due to busy working schedules, they would need to be more proactive and take part in self-directed learning in order to build up their confidence and knowledge.

"To be honest if the training pack is too detailed it will prevent a lot of people from doing it. but something compact with patient frequently asked questions and the treatment options and side effects and how to manage it will be good enough"

-CP_08

Despite the acknowledged barriers, pharmacists welcomed the idea of changes to practice and were keen to provide support as part of existing services such as Medicines Use Reviews (MURs) or Healthy Living

Pharmacy campaigns, acknowledging that knowledge on local cancer support services would fit nicely with the agendas of the latter.

“You know now most pharmacies are Healthy Living pharmacies and they have to do promotional campaigns. Perhaps one or two of them could be on Cancer Support. We can get people from the local support groups to come and man the promotional desk and talk to customers”

- CP_03

Pharmacists, like the survivors, highlighted the need for some sort of check-up or review. Suggestions for such a review included targeting breast cancer medications through the existing New Medicines Service (NMS), or introducing a targeted cancer MUR. It was also acknowledged that a lot of the topics survivors needed advice on, such as healthy living, understanding why their medicines were prescribed and medicine-related problems are all things that could be provided as part of the MUR service.

Community pharmacists proposed being actively involved in care pathways and suggested that a named pharmacist (chosen by the patient) should be cited on the treatment plan. It was also noted that care experiences could be improved if survivors agreed to share a copy of their treatment plan or discharge summary with their community pharmacist. As part of the Recovery Package recognised in NHS England’s Five Year Forward View, Macmillan have developed an e-Health Needs Assessment (e-HNA). This is a questionnaire completed online by the survivor and used by healthcare providers to support with care planning.¹³ Although it is part of the national agenda for the NHS, it is not clear whether many survivors are being offered this service currently. One of the suggestions of the focus groups was therefore that community pharmacists could carry out the e-HNA for breast cancer survivors as part of their review.

“MUR with a named Pharmacist who has a referral pathway so if needed could get patient back into system if necessary or any concerns and seen by the right person”

-CP_01

The survivors’ suggestion to introduce a welcome pack was well-received by pharmacists as a means to encourage early contact with the pharmacist and promote pharmacist roles and services. They felt however that the inclusion of free product samples would be difficult to fund and organise, and deemed it unnecessary. One pharmacist noted that it would be particularly useful to tailor the welcome packs to detail the services offered in the individual pharmacy. Another suggested that a voucher system could be adopted, and these could be issued along with the medical exemption card.

“Cancer patients already get free prescriptions via a medical exemption card. Could a welcome pack be provided at the same time as issuing the exemption card? [...] Or rather than the actual pack, a voucher to be redeemed at their local pharmacy.”

- CP_05

The final intervention suggestion involved setting up a cancer information drop in clinic that could be held at regular intervals and run by a second pharmacist with specific training. It was noted that in order to be worthwhile, the scope would have to be widened to include all cancer types and all stages of the cancer journey, including prevention.

“It could be run as a weekly drop in clinic using the consultation room so anyone worried about cancer, be it themselves or a family/friend, current or past patients or even those who may be at risk or believe themselves to be at risk can drop in for a review or for some signposting/reassurance. For example, women on HRT hear conflicting information about risk, yet the risk associated with obesity is underplayed. If the speciality is widened, someone could come in to have their mole checked, it’s really easy to spot something that looks suspect and requires referral. We’d need the training and we’d also

need to exercise proper clinical judgement as it wouldn't work if we were too risk averse- we'd be referring everyone (this is getting back to the problems already highlighted by patients)"

- CP_09

Stakeholder perspectives

Interviews were conducted with five stakeholders; a Macmillan GP, a hospital-based oncology pharmacist, a representative from a cancer charity, an LPC chair and a stakeholder within pharmacy commissioning.

Stakeholders were very positive about community pharmacists taking on an increased role to support survivors and agreed that community pharmacists would be well-placed to provide the right information at the right time, and to signpost to local support services. Stakeholders were also keen to collaborate with pharmacists where possible through shared training and establishing local networks.

In terms of referral into a named community pharmacy, the hospital oncology pharmacist also suggested that there could be a process put in place to refer the survivor back into the hospital if there was a problem.

Stakeholders were largely supportive of the idea of adapting national services such as MURs to target cancer survivors, but it was acknowledged that following the Murray Review of Community Pharmacy Clinical Services¹⁴ and the work carried out by the Community Pharmacy Future project¹⁵, the current MUR service may change to make way for new care pathways and services that incorporate more long-term care and utilise pharmacist prescribers.

Recommending pharmacy products for the management of cancer-related side effects was a well-received suggestion and something, it was agreed, that could feasibly be addressed on a national level. The oncologist pharmacist was aware that samples of things like moisturisers could be supplied by the manufacturer and felt this could easily be organised. They also noted that in the hospital setting, recommendations are restricted to the products available on the formulary, so the advantage of community pharmacy is that they have access to a wider range of products.

"So if I shared our formulary or our recommended products, if someone got a rash because of whatever, then say 'this is what we would try with the patients' so that the pharmacist was aware of that and then if obviously the patient comes in and says 'I've tried it, its not working' then they can be a bit more exploratory, I suppose, and say 'Well we actually have this product available that the hospital doesn't have available. It's similar but it's got a slightly different ingredient; maybe have a go with this; see if this works.'"

-Stakeholder_01

Discussion

Key findings

Survivors often feel isolated and abandoned after being discharged from hospital, and require additional care and support in the community setting throughout their cancer journey. Key care needs for survivors include more proactive care and better information on clinical advice and community services. A holistic approach to care was needed; encompassing emotional support and general health and wellbeing advice. Appropriate signposting to support services and improved continuity of care were also key requirements.

Community pharmacists were keen to expand their roles and acknowledged considerable scope to proactively support survivors and their family and friends; ensuring they have access to the right care at the right time. Whilst the lack of time and funding were noted as key barriers to introducing new services, pharmacists saw opportunities to increase support as part of existing services such as MURs or HLP campaigns.

Stakeholders were likewise in favour of community pharmacists taking on an increased role to support survivors. Local-level collaborations amongst community pharmacists, other healthcare providers and local

charities received a positive response. The importance of challenging public perceptions of community pharmacists was also noted.

Whilst some of the suggested improvements, such as formally including community pharmacists in the breast cancer treatment pathway, or updating the existing MUR service, may be more challenging to implement, many of the suggestions appeared very feasible in the shorter-term. Findings highlighted many small changes that pharmacists could make within their current practice.

The MUR service currently provided in community pharmacy involves an annual medication check-up for those on multiple medications, along with healthy living advice. Although survivors reported that they would like a review, few were aware of or had been provided with an MUR. This is most likely due to the requirement that 70% of MURs conducted should fall into specific target groups, of which breast cancer is not one. Therefore, many survivors would not be eligible for this service and a clinical check-up of some description was something they felt was needed. Already a nationally funded service, community pharmacists should be ensuring that all eligible breast cancer survivors are offered an MUR.

Strengths and limitations

This study utilised focus groups and iterative analysis techniques to generate new ideas on opportunities for community pharmacists to better support breast cancer survivors, taking a range of perspectives into account.

This project focused on female breast cancer only, and whilst this is a good starting point given its high prevalence and need for long term treatment, the long-term feasibility of future interventions and services may depend on a service that provides support for all survivors of all types of cancer.

Whilst community pharmacists and stakeholders were recruited from across the country, for the community pharmacists involved were only recruited from Warwickshire, Lincolnshire and Nottinghamshire. The data did highlight considerable differences between experiences, but findings may not be an accurate reflection of the experiences nationwide.

The involvement of stakeholders in this study is limited, and whilst this data is useful to inform future work, the views of a single representative cannot reflect those of others in the field. Again, issues such as geographical location may affect individual experiences. With this in mind, future work may therefore need to examine stakeholder views in more depth.

Next steps and future outcomes

In the short term, raising the awareness of survivor care needs and encouraging individual community pharmacists to make small changes to their practice; such as having conversations with survivors, connecting with support services and healthcare providers in their local community, undertaking training and organising in-store events such as HLP campaigns can improve survivor experiences.

Findings have been discussed with relevant organisations (a cancer charity, a pharmacy chain) who may be able to utilise these at organisation level and support in shaping the future of the community pharmacy.

This study has identified several potential features of a new service or intervention. Given the changing landscape of pharmacy services, future work should aim to explore how these changes could affect survivor experiences. It may also be of value to explore the feasibility of developing interventions aimed at all cancer survivors; not just those with breast cancer. Following this, findings can be used to further inform the design and piloting phases of a future service or intervention.

Conclusion

Through exploring the perspectives of breast cancer survivors, community pharmacists and relevant stakeholders, this study provides insight into the opportunities for community pharmacists to take on a

larger role in breast cancer survivorship services. As individual practitioners, community pharmacists can make changes to their practice through having more proactive conversations with survivors, networking locally and undertaking further training. Going forward, these findings can also be used by those involved in healthcare service development and policy-making to inform the design of services or interventions.

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Appendices

Appendix 1: Interview schedule

Survivor Focus Group Interview Schedule

Briefing

- The purpose of this focus group is to discuss the experiences of people living with and after breast cancer when being cared for in the community, and to understand what additional care or support might be needed
- The focus group will take approximately 2.5 hours
- *Confirm that all participants have read and understood the participant information sheet and signed the consent form*
- *Confirm all participants have completed the survey*

During the focus group

Examples of themes to be discussed:

- Medicines-related problems, e.g.: side effects, adherence, interactions, other
 - Current care provided by GPs, pharmacists and other community-based healthcare professionals
 - Roles of healthcare professionals - How did these change throughout cancer experience?
 - Accessibility of care – convenience and frequency of consultations, impact on life
 - Services provided - e.g: Boots Macmillan Information Pharmacist services, Medicine Use Reviews, Cancer Care Reviews, other care or consultations
1. *Positive experiences of care, particularly provided by pharmacists*
 2. *Negative experiences: medicines problems that were not resolved efficiently, lack of care/information. Where in cancer experience did these problems occur?*
 3. *What could be done to improve care experiences? What additional care or support would have helped? Was there anything that could have been done differently? What additional services could pharmacists offer? – Opinions of each of these?*

Closing

- *Summarise the discussion*
- *Would anyone like to add anything?*
- *Thank all participants for their contributions*



Pharmacist Focus Group Interview Schedule

N.B. The content of the focus group will be based on the findings from the survivor focus groups. The final interview schedule will therefore be drawn up following analysis of this data.

Briefing

- The purpose of the focus group is to discuss potential opportunities of a community pharmacy intervention to support and improve the health outcomes of breast cancer survivors. It will aim to establish the views of this group as potential service providers, and consider any feasibility or operational issues
- The conversation will be based on survivor's ideas about how their experiences of breast cancer might have been improved by increased pharmacist involvement
- The focus group will take approximately 1.5 hours
- All comments and responses should be typed
- *Confirm that all participants have read and understood the participant information sheet and consent form*
- *Confirm all participants have signed and returned the consent form*

During the focus group

Content to be confirmed

Closing

- Does anyone have anything else to add?
- *Thank all participants for their contributions and close the discussion*

Stakeholder Meeting Schedule

N.B. The content of the meeting will be based on the findings from the survivor and pharmacist focus groups. The final interview schedule will therefore be drawn up following analysis of this data.

For stakeholders unable to attend, the presentation slides will be sent via email, and the discussion will take place in the form of a telephone interview.

Briefing

- The purpose of this meeting is to discuss perspectives of relevant stakeholders surrounding the opportunity for developing a community pharmacist-led intervention to provide support and improve health outcomes of breast cancer survivors
- The meeting will take approximately 1.5 hours, and will consist of a presentation followed by a discussion
- Confirm that all participants have read and understood the participant information sheet and consent form; signed the consent form and retained a copy of the information sheet

Presentation

Present a brief background to the research and findings of the study so far, summarising the issues faced by survivors and how pharmacists propose to address these

Discussion

- *Establish views and requirements of stakeholders*
- *Discuss factors to consider when developing a service proposal, or considering commissioning prospects*

Closing

- *Summarise the discussion*
- *Does anyone have any other comments to add?*
- *Thank all participants for their contributions*

Appendix 2: Field notes from PPI activity and Topic Guide

Field Notes

- Family History, genetic links
- Menopause – am I postmenopausal? which medicines are safe? Symptoms vs side effects of medicine
- Spreading or recurrence – lack of support, lack of checks/exams, no follow up care
- Side effects – (Sweating, hot flushes, weight gain, cramps, bleeding), severity, how long they last for, other peoples' attitudes, no information given, no medicine counselling
- Appearance – couldn't wear makeup because sweating was so bad, hair loss/ wig support
- Medication – danger of recurrence, effectiveness of AI vs tamoxifen, side effects, red flag symptoms, other medications to help with side effects – clonidine, SSRIs
- Proactiveness – changing meds, looking for support from charities, family history
- Charities & support – Breast Cancer UK, Maggie's – patient support group (leaflets given at hospital), online support, chemotherapy clinic had community feeling, Macmillan (written support booklet)
- GP - GP didn't want to get involved. No CCR. No follow up or contact from primary care. Not wanting to bother GP, feeling embarrassed for worrying about recurrence
- Hospital support - Good support from hospital during first six months. – surgeon, breast cancer nurse, radiotherapy. Yearly check-ups needed. Hospital care dropped off after six months. Very disappointing aftercare. No check-ups after six months one year in hospital – concerns about recurrence.
- What can pharmacists do - Could have done with regular chats and support from pharmacy, pharmacists need a better understanding of experiences and problems faced throughout whole journey, written information/ booklets, vitamins and supplements guide, training of how to counsel patients, emotional support, when to refer- red flags, fast tract referral, no information given from hospital pharmacist, pharmacists need better knowledge, need to help manage side effects and warn about recurrence, signposting, more detailed knowledge of most common cancers, Could pharmacists be trained to check glands for lumps etc? Knowing where glands are, etc
- HCPs need to be more proactive
- Herceptin care and process
- Emotional support – dealing with fear of recurrence
- Lack of support surrounding mastectomy – what to expect – appearance, healing, lack of care afterwards – carrying heavy drains, showering, facing a mirror, lots of emotional trauma, would have liked to hear from other patients, or seen photos - have been prepared better

Focus Group Topic Guide

General feelings about the care from community-based healthcare providers

- Hospital vs community

Changes in care throughout journey during treatment vs follow up

- Hospital aftercare/follow up
- Were HCPs proactive/interested?

Positive and negative experiences

- Did they feel knowledgeable/empowered as a patient?
- What were best sources of support or care?
- Was enough care provided?
- Right levels of knowledge/interest from HCPs? Approachability
- Accessibility (frequency) Impact on day to day life, local services
- Right sort of care? What could have been done differently?
- Medicines related problems – switching, early discontinuation, side effects

Care and services offered/provided

- GPs – CCR
- Pharmacists – MURs, BMIP, PILs
- Others
- Sources of information
- Charities and support groups
- Other patients - peers

Additional support needed & from whom

- Medicines
- What to expect when going through various treatments – mastectomy, side effects of ET, Herceptin, CT, RT
- Managing side effects
- Recurrence/spreading
- Menopause
- Family history
- Getting back to 'normal' life
- Appearance
- Emotional support
- Sources of information
- Social life

What could pharmacists do to help? Opinions. Will the pharmacist fit the role?



**How can we
improve care for
women living
with breast cancer?**

**IF YOU HAVE BEEN TREATED FOR BREAST CANCER
WE NEED YOUR HELP**

We are researching how care provided to people living with and after breast cancer could be improved by new community pharmacy services.

We need:

- female volunteers
- over 18 years of age
- started taking medicines for breast cancer at least 2 years ago
- have been looked after in the community (by GPs, nurses, pharmacists, etc.)

If this is you, we would like to invite you to take part in a discussion about your experiences and how care could be improved.

**FOR MORE INFORMATION,
PLEASE SPEAK TO A MEMBER
OF YOUR PHARMACY TEAM**

Alternatively, contact:

Lydia Tutt

Division of Pharmacy Practice and Policy,
School of Pharmacy,
University of Nottingham

Email: paxlt1@nottingham.ac.uk

Telephone: **0115 82 32285**



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Appendix 4: Inclusion and exclusion criteria for participants

Table 1 Inclusion and exclusion criteria for survivors

Inclusion criteria	Exclusion criteria
Able to give informed consent	Unable to give informed consent
Able to understand or communicate in English	Unable to understand or communicate in English
Female	Male
Over 18 years of age	Under 18 years of age
Treated for breast cancer within primary care in England	Received no treatment for breast cancer within primary care in England
Minimum of two years since the first diagnosis of breast cancer was confirmed	Less than two years since the first diagnosis of breast cancer was confirmed
Living within (or able to easily travel to) the selected geographical areas of recruitment	Not living within (or able to easily travel to) the selected geographical areas of recruitment

Table 2 Inclusion and exclusion criteria for community pharmacists

Inclusion criteria	Exclusion criteria
Currently practising community pharmacy in England	Not currently practising community pharmacy in England

Table 3 Inclusion and exclusion criteria for stakeholders

Inclusion criteria	Exclusion criteria
Job or voluntary role relevant to the development of breast cancer services in community pharmacy in England	No job or voluntary role relevant to the development of breast cancer services in community pharmacy in England
(Self-defined) Knowledge of current practice regarding cancer services in primary care, specifically community pharmacy	No knowledge (self-defined or otherwise), of current practice regarding cancer services in primary care, specifically community pharmacy