Exploring the acceptability and benefits of group pretreatment consultations for people receiving systemic anticancer therapy

Emma Rowland and Catherine Oakley

Abstract

Background Patients with cancer receiving systemic anticancer therapy (SACT) historically attended a one-to-one hospital pretreatment consultation (PTC) with a SACT nurse who provided educational and psychological support. However, these PTCs had limitations for patients, relatives and the SACT nurses delivering them.

Aim To develop a psychosocial and educational group intervention to support the SACT informational needs of patients with cancer and their relatives.

Method A multi-method qualitative study design was adopted. A group PTC was developed through: observations of one-to-one nurse-led PTCs and doctors obtaining patients’ consent for SACT; two focus groups with healthcare professionals (∙n=12); semi-structured interviews with healthcare professionals (∙n=6); two focus groups with patients who received SACT (∙n=10) and their relatives (∙n=2); and semi-structured interviews with patients who received SACT (∙n=4). The intervention was presented in a workshop and SACT nurses (∙n=10) were trained in its delivery.

Findings Overall, the intervention proposal appeared to be received positively by patients, relatives and healthcare professionals. However, questions remained over the feasibility and acceptability of delivering group PTCs.

Conclusion The group PTC seems to be promising, although it requires piloting. Group PTCs are expected to encourage patients and relatives to manage and report symptoms, by promoting family-centred care. It is also anticipated that the group approach will make better use of SACT nurses’ time so they are more available to provide individualised care during treatment administration, while also reducing their emotional labour.

Background Around 3 million people in the UK are living with cancer, and by 2025 this number is likely to rise to 3.5 million (Macmillan Cancer Support 2022). According to Cancer Research UK (2023), there are 375,000 new cases of cancer each year in the UK. Many patients require curative or palliative treatment, primarily in the form of surgery, systemic anticancer therapy (SACT) and/or...
radiotherapy. Approximately 20% of patients in England receive SACT (CancerData 2023). SACT can cause a range of side effects; approximately 25% of patients experience suboptimal health and/or disability after treatment, affecting their ability to perform daily activities and their overall quality of life (Epstein et al 2021). SACT can also cause life-threatening side effects including neutropenic sepsis and thromboses, which require vigilance by patients and caregivers. However, many patients find it challenging to engage with discussions about life-threatening side effects due to fear, which reduces help-seeking behaviour (Oakley et al 2017).

People with cancer also encounter various psychosocial and emotional challenges as they process the implications of their diagnosis and treatment (Costa et al 2016), as well as potential financial toxicity caused by reduced productivity at work or an inability to work (Pearce et al 2019). The support and care provided by relatives is important for patients’ physical health and psychosocial and emotional recovery (Ream et al 2021). However, research shows that relatives often feel isolated, ill-prepared, frightened and anxious in terms of supporting patients through their diagnosis and treatments due to inadequate information (Tsianakas et al 2015). This can lead to suboptimal mental health and, in some cases, greater anxiety and depression than that experienced by the patient (Sklenarova et al 2015). This could adversely affect relatives’ ability to provide adequate care for the patient (Northouse et al 2012), poses potential risks to their safety and can reduce the patient’s adherence to treatment (Waller et al 2014).

Receiving a cancer diagnosis and undergoing treatment is emotionally challenging for patients and their relatives (Prescott et al 2016), often changing family dynamics and placing strain on relationships (Fisher et al 2021, Alfaro-Díaz et al 2022). Educational (informational) and psychological support is essential for patients with cancer and their relatives to understand and accept the diagnosis and the psychosocial, emotional and financial implications of the condition and treatment on their lives.

Pretreatment consultations
Historically, patients with cancer at a London hospital were prepared for SACT by a 45-60 minute, one-to-one pretreatment consultation (PTC) with a SACT nurse who provided educational and psychological support. However, patients and SACT nurses noted several limitations of the PTC. For example, patients often left the PTC feeling afraid, isolated and/or frustrated, which led to suboptimal information recall. Furthermore, many patients attended their PTC alone, leaving their relatives feeling disempowered to support and care for them. SACT nurses felt emotionally exhausted by the content of the consultation and often struggled to remember what was communicated to each patient, reducing the quality of information exchange. PTCs could be improved to better assist patients and their relatives in understanding the treatment and its side effects, thereby reducing the emotional labour of SACT nurses and increasing capacity in the context of a national SACT nursing shortage (The Royal College of Radiologists 2023).

To support the development of a new PTC, the study detailed in this article was underpinned by family systems theory (Priest 2021), which recognises that people do not experience illness in isolation, since a diagnosis of a condition will also affect a person’s relatives and friends. Therefore, it was important that the new PTC was attended by patients and relatives to prepare them for SACT and its side effects.

Research shows that providing quality cancer information to patients and relatives is acceptable and effective (Prescott et al 2016), fostering effective communication, which can lead to better coping with the diagnosis and adaption to the disease and treatment (Valente et al 2021). Previously, interventions designed to prepare patients for cancer treatment have been predominantly aimed at the patient to the exclusion of relatives (Waller et al 2014). In response, Tsianakas et al (2015) developed a ‘Take Care’ intervention for patients-carers that increased carer satisfaction and showed a statistically significant improvement in carers’ understanding of SACT side effects and confidence in supporting the patient undergoing SACT. Building on these studies, the authors wanted to develop an intervention to support both patients and their relatives.

**Aim**
To develop a psychosocial and educational group intervention to support the SACT informational needs of patients with cancer and their relatives. The intention was to enhance patient safety and patients’ and relatives’ psychosocial and emotional well-being during treatment, to reduce SACT nurses’ emotional labour in conducting multiple pre-SACT appointments and to increase SACT nursing capacity.

**Implications for practice**

- Group pre-treatment consultations (PTCs) may be an effective way of engaging patients with systemic anticancer therapy (SACT) and supporting information recall
- Relatives could be empowered to support patients during SACT treatment as a result of attending group PTCs
- SACT nurses’ delivery of information and job satisfaction could be enhanced by group PTCs, and their emotional labour could be reduced
- Group PTCs could help to increase capacity where SACT nurses are in high demand
Method
The UK Medical Research Council model for developing complex interventions supported the development of the group PTC intervention (Skivington et al 2021). A two-stage qualitative multi-method study design was used. The study began in 2017 and concluded in September 2018.

Stage one consisted of a qualitative health researcher (ER) collecting qualitative data from key stakeholders including oncology healthcare professionals, people with cancer receiving SACT and their relatives. The inclusion criteria for stage one are shown in Table 1. Two focus groups were conducted with healthcare professionals (n=12) and individual semi-structured interviews were conducted with healthcare professionals (n=6) at a London hospital. Observations included doctors obtaining patients’ consent for SACT and one-to-one nurse-led PTCs (n=13, 20 hours). Patients who had received SACT (n=10) and their relatives (n=2) participated in two focus groups, and patients who had received SACT (n=4) participated in semi-structured interviews. Data were collected to ascertain stakeholder experiences of the current one-to-one PTC and understand whether a group PTC would be acceptable. Furthermore, views on what the new intervention might look like in practice in terms of content, duration, group form and structure were sought. Interview and focus group schedules are available on request.

The interviews and focus groups lasted for between 60 minutes and 90 minutes, and were audio recorded and transcribed verbatim by a third-party transcription company (McLellan et al 2003). Observational notes were transcribed into ethnographic transcripts (Emerson et al 2011). All qualitative data were inputted into data management software and analysed using thematic analysis (Braun and Clarke 2021).

In stage two, SACT nurses (n=10) attended a four-hour workshop in which the intervention was presented and discussed. They were then trained in delivering activities that facilitated communication with relatives. The inclusion criteria for stage two are shown in Table 2.

Healthcare professionals were recruited through a multidisciplinary team meeting where the study was presented by the authors (ER and CO). Healthcare professionals contacted the first author (ER) directly to participate. Patients and their relatives were identified through their post-SACT follow-up meetings and were verbally given information about the study. All prospective participants were given a participant information sheet and a minimum of 24 hours to consider participation.

Ethical considerations
Ethical approval was sought and obtained from London – Camden and King’s Cross Research Ethics Committee. Since people with cancer are considered vulnerable participants, the authors were mindful of the effects that participating in the study might have on their psychological well-being. Written consent was obtained from all participants, and they were able to stop their interviews at any time and revoke their participation without question at any point. Participants were provided with signposting information to psychological support. All data were anonymised and stored securely.

Findings
The cancer types for the 14 patient participants were as follows: breast (n=4), colorectal (n=3), ovarian (n=2), prostate (n=1), myelofibrosis (n=1), Hodgkin’s lymphoma (n=1), lung (n=1), and liver and colorectal (n=1).

Findings are grouped by intervention development stage:
» Current one-to-one PTC.
» Developing a group PTC.
» Intervention workshop and training.

Table 1. Inclusion criteria for stage one

<table>
<thead>
<tr>
<th>Participants</th>
<th>Inclusion criteria</th>
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<tbody>
<tr>
<td><strong>Patients</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diagnosed with cancer</td>
</tr>
<tr>
<td></td>
<td>Received at least one cycle of systemic anticancer therapy (SACT)</td>
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<tr>
<td></td>
<td>Able to read and speak English</td>
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<td></td>
<td>Aged over 18 years</td>
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<tr>
<td><strong>Relatives</strong></td>
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<tr>
<td></td>
<td>A relative, partner or supportive friend identified by the patient</td>
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<tr>
<td></td>
<td>Able to read and speak English</td>
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<td></td>
<td>Aged over 18 years</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td></td>
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<tr>
<td></td>
<td>Any healthcare professional delivering care and SACT treatment to patients with cancer at the host site</td>
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</tbody>
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Table 2. Inclusion criteria for stage two

<table>
<thead>
<tr>
<th>Participants</th>
<th>Inclusion criteria</th>
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<tbody>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Systemic anticancer therapy nurses working at the host site</td>
</tr>
<tr>
<td></td>
<td>Able to read and speak English</td>
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<td></td>
<td>Aged over 18 years</td>
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Current one-to-one pretreatment consultation

The current one-to-one PTC was discussed with healthcare professionals, people with cancer and relatives separately. Thematic analysis derived four themes: reaffirming and checking information; overwhelmed patients; emotionally fatigued nurses; and family support.

Healthcare professionals indicated that the delivery of information in one-to-one PTCs varied, as they tried to tailor the consultation and language they used to each patient:

- ‘When you’re sitting down with a patient, trying to understand “what’s this person’s level of understanding? How can I get this across to them? And how can I engage them?” the right delivery is key.’ (Healthcare professional 4, acute oncology sister)

Despite language differences, most healthcare professionals agreed that the purpose of the PTC was to ‘reiterate’, ‘re-affirm’ and ‘complement’ the information provided by the doctor during the SACT consent appointment. They considered the most important information to provide was: treatment side effects, events of the day and acute oncology service contact details, as well as checking the patient’s veins, providing a thermometer and ‘encouraging that patient-professional relationship’ (Healthcare professional 5, pharmacist).

However, nurses stated that conducting multiple, consecutive PTCs resulted in some information loss:

- ‘We do five [PTCs] in a day, sometimes, you get to the fourth one and you think “have I said that?” They all just blur into one.’ (Chemotherapy nurse, focus group B)

In addition, healthcare professionals noted that patients experienced challenges in recalling all the information given:

- ‘We sit and give a load of information… it’s amazing when we sit with the patient next week and they didn’t really take any of it in at all.’ (Healthcare professional 4, acute oncology sister)

While patients and relatives appreciated that the PTC was ‘comprehensive’, they often felt overwhelmed and experienced suboptimal information recall:

- ‘She was saying a lot, I honestly can’t remember most of it.’ (Patient 1, ovarian cancer)

Patients were most likely to recall information about side effects, including alopecia, dry skin and sickness and associated preventive measures, such as cold caps, wigs, creams and antiemetics. Patients and relatives also tended to recall access to free therapies, such as reflexology, counselling and support groups, but many did not remember discussions about serious risks associated with sepsis or who to contact if they experienced side effects.

Despite feeling overwhelmed by the information, patients and relatives felt ‘something was missing’ or the consultation was ‘a bit rushed’ (Patient 1, ovarian cancer). Many patients wanted more discussion about prophylactic treatments such as the cold cap, and were not told about different treatment reactions, delayed or late side effects which would better inform treatment decisions:

- ‘I was afraid of my hair falling out… she said you can wear a cap. I don’t think this was explained enough because in hindsight I think I might have tried [it].’ (Patient 1, ovarian cancer)

- ‘There were bits of information I could have been told that I wasn’t. I had a bad reaction to the chemotherapy – hot flushes, [heart palpitations], spasms in my back, jerking in the chair. I wasn’t told this could happen – if I was, I would have been a lot calmer.’ (Patient 1, ovarian cancer)

Several patients said while they were encouraged to ask questions in their consultation, they often did not do so because the session felt rushed, they felt overwhelmed or they did not want to ask ‘silly questions’.

Several patients turned to charities or support groups instead:

- ‘I phoned [Target Ovarian Cancer] for some support… she talked me through everything, I had questions [I didn’t ask in clinic because I thought] “Am I being stupid here?” Are they gonna see me every time and think “Oh there, that silly woman who asked that silly question”… it was nice to speak to someone anonymously.’ (Patient 1, ovarian cancer)

Patients felt their emotional and psychological well-being was not addressed because ‘it was all quite clinical… there wasn’t any personal bits’ (Patient 1, ovarian cancer). Some patients felt like they were on a ‘conveyor belt’ (Patient 7, breast cancer). Some expected a lack of personal connection because ‘they’re seeing people all the time’ (Patient 9, prostate cancer). Others wanted their healthcare professional to acknowledge the emotional burden:

- ‘These treatments aren’t without huge emotions and it’s important to recognise that.’ (Patient 1, ovarian cancer)

Despite this assertion, healthcare professionals disclosed they often became fatigued by the ‘emotional weight’ of the...
Developing a group pretreatment consultation

The concept of developing a group PTC was discussed with healthcare professionals, people with cancer and their relatives separately. Thematic analysis derived four themes which focused on acceptability of the group PTC, content and structure. These themes were: benefits and limitations; patient allocation; style and substance; and family involvement.

Healthcare professionals had mixed views on acceptability. Some considered group consultations to be a good idea in theory but suggested that they might be too challenging to deliver. They considered the acceptability of group consultations for all patients, as ‘not all families are open to talk’ (Healthcare professional 3, survivorship co-ordinator). As a result, there were questions about the process for those patients who did not want to join a group or were unable to join due to disability or language barriers:

‘I don’t feel [the chemotherapy nurse] prepared me for it.’ (Patient 1, ovarian cancer)

Finally, some patients found visiting the treatment suite during the consultation frightening:

‘I’d never seen a [treatment] suite, it was quite scary. I don’t feel I was prepared to see all those people sitting there, some of them looking quite poorly... with the wires and no hair, I found it quite stressful, quite traumatic. I don’t feel [the chemotherapy nurse] prepared me for it.’ (Patient 1, ovarian cancer)

Some healthcare professionals rejected the group consultation idea, believing that one-to-one PTCs were appropriate for tailoring information to individual patients’ needs and that group PTCs were about cost saving:

‘I’m not totally persuaded... this is beginning to sound like four hours out of my life as against information that’s tailored to me to meet my requirements. It’s all about cost containment, it’s got nothing to do with quality.’ (Healthcare professional 1, consultant)

Aligning with this sentiment, other healthcare professionals stated that patients ‘might not feel special...or [not given] enough attention’ (Healthcare professional 6, pharmacist) or unable to ask personal questions in a group setting:

“They might have specific questions they might not ask... it can be a financial problem or fertility, other things like that.” (Healthcare professional 6, pharmacist)

A minority of patients were not in favour of group PTCs. Reasons for this included that they were ‘not a sociable person’ (Patient 2, Hodgkin’s lymphoma) or considered their cancer diagnosis and treatment to be a ‘private matter, not to be shared’ (Patient 14, breast cancer).

Most patients and relatives thought group consultations were a ‘good’ or ‘excellent’ idea, and group PTCs could benefit relatives as they could ‘ask questions’, ‘meet other relatives in the same boat’ (Patient 3, colorectal cancer) and learn about available support.

‘For my family, my children, there has been nothing... there is no support network. I am sure they have loads of questions they don’t want to ask mum about, as mum might get upset. It would be nice if they could talk to other people.’ (Patient 1, ovarian cancer)

In considering the content of the group PTC, healthcare professionals stated the most important information to convey was:

- Signs and symptoms of neutropenic sepsis.
- Side effects of SACT treatment such as nausea, fatigue, diarrhoea, vomiting, peripheral neuropathy, alopecia, mouth ulcers, taste changes, spinal cord compression and shortness of breath.
- Understanding what constitutes an oncological emergency.
- The importance of temperature checking and how to use a thermometer.
- Emotional support.

Healthcare professionals considered whether they could incorporate pre-recorded videos conversations around diagnosis and treatment (Chemotherapy nurse, focus group A).

For emotional support and to facilitate information recall, many patients discussed the importance of bringing a family member, usually their partner, to help ‘remember the bits you’ve forgotten’ (Patient 1, ovarian cancer) and to share the experience.

‘[My husband] came with me because when they’re telling you these things, you’re not taking it all in...and if you have someone else with you, they’ll remember the bits you have forgotten.’ (Patient 1, ovarian cancer)

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or whether patients and relatives should be separated during the consultation to deliver individual information. Many healthcare professionals considered the benefit of bringing in ‘expert patients’ to share personal experiences.

Healthcare professionals, patients and relatives considered how the group PTCs should be constructed. Most patients stated the groups should be grouped by cancer type, and some healthcare professionals concurred. While patients were not interested in other cancers, they also acknowledged that there might be challenges in holding groups for specific cancer types and that for practical and logistical reasons cancer types might need to be mixed:

‘How many [people with ovarian cancer] are in the building? There might be two, there is no point just two of you sitting there.’ (Patient 1, ovarian cancer)

Grouping patients by treatment type was also considered:

‘I mean if you look at [women with breast cancer], I mean most of them get FEC-T [chemotherapy]… they’ll probably all get the same side effects. They’ll probably all be in the same clinic, same time. But that isn’t going to work for the colorectal patients… you get different schedules.’ (Healthcare professional 5, pharmacist)

No patients or relatives considered mixing cancer and treatment types, but some healthcare professionals did:

‘Nurses are very protective of their patients, but actually if you throw them together it works really well, it opens up conversations. Ultimately yes there are some specifics to that tumour group but there’s so many overlaps in how they feel, how they cope, how they manage financially, physically, emotionally, family wise that it actually doesn’t matter if you’ve had breast cancer or a melanoma – they can be very similar.’ (Healthcare professional 3, survivorship co-ordinator)

In considering the number of group participants, many patients suggested four to six families, with the rationale being:

‘Not too many… you don’t want the group too big that you are not gonna be able to ask your questions.’ (Patient 1, ovarian cancer)

Others considered the room size to deliver the session, the duration, the relatives that patients might want to bring and the effect of discussions:

‘I guess it depends on the space and especially if we’re having break out groups. Personally I think if it’s 100, it would be too many. Too little is also not good because

then you just have two families… maybe a total, maximum of like, 30?’ (Healthcare professional 3, survivorship co-ordinator)

‘I think even 10, 15, maximum 20. Yeah… the more people who are there, it will be like more discussions.’ (Patient 14, breast cancer)

Most patients and relatives stated they would bring their partner to the session. One healthcare professional reflected that patients’ decisions may depend on their age and gender:

‘More commonly males are on their own… more commonly the older generation come with partners and the younger generation come with brothers, sisters, mothers.’ (Healthcare professional 5, pharmacist)

In considering the session duration, many healthcare professionals, patients and relatives felt an hour was sufficient, while others talked about having multiple sessions:

‘About an hour, no longer… you just want to go home. If you had a few sessions you would come back because [you] want to know more.’ (Patient 1, ovarian cancer)

Healthcare professionals tended to believe that the appointment needed to be more than one hour. Those considering longer sessions talked about the need for these to be broken up into several short information sessions with time for questions:

‘Four hours, if you say that to somebody, you’re like, “Jesus!” But you say like half an hour with Macmillan, then tea and cakes or a tour round the cancer centre and then back down to speak to a survivor and another break, lunch, and then come back and then – breaking up the engagement, allowing them to digest the information.’ (Healthcare professional 5, pharmacist)

Patients were asked whether they would like to engage in activities during the group consultation. Many patients thought this was a good idea to break up information giving and to make the sessions more fun and engaging:

‘I think [being lighthearted is] a good way of doing things… although I think you have to be mindful of who is in the group.’ (Patient 14, breast cancer)

While activities were welcomed, some participants stressed the importance of getting the balance right between fun and the seriousness of the topic; many felt using humour would be inappropriate:

‘You cannot just joke on something that is serious but… it’s a delicate situation. It really depends on the person as well.’ (Patient 14, breast cancer)

Finally, healthcare professionals discussed who should deliver group PTCs, with most
believing it should be nurse-led and, in particular, SACT nurse-led:

‘Chemo nurses would be nice because they see the patient every day and I think they’ve got such good hands-on experience…’

(Healthcare professional 5, pharmacist)

Several healthcare professionals suggested SACT nurses should deliver the main content with drop-in sessions delivered by the acute oncology service, counsellors, therapists, charities and pharmacists. One participant believed psychologists should deliver the intervention:

‘I don’t think that’s something that could be delivered by a band 6 nurse… that needs to be delivered by someone with counselling skills. Dimbleby psychologists do a lot of group facilitation.’

(Healthcare professional 4, acute oncology sister)

Many healthcare professionals stated the person delivering the sessions required clinical experience and facilitator and/or counselling skills to manage group dynamics:

‘I think as nurses we’re quite well prepared for patients, but I think maybe dominant families might be something else. I’d need more managing techniques.’

(Healthcare professional 2, cancer information specialist)

Intervention workshop and training

A group PTC was developed based on the findings. SACT nurses attended a four-hour workshop, including a 30-minute presentation of findings, an outline of the group PTC and discussion of a draft delivery protocol. Thematic analysis derived three themes: benefits for patients and family members; reservations, confidence and managing false information; and activities and training.

The nurses were optimistic about the group PTC stating they would be ‘really helpful’ (Chemotherapy nurse, focus group A) and ‘beneficial to patients’ (Chemotherapy nurse, workshop) and they thought groups would facilitate greater family involvement in the patient’s treatment.

However, the nurses still had reservations about the mixing of patients, stating there would be some who do not want to be involved in groups or may spread misinformation:

‘As much as there are some patients that can teach other patients, potentially [some] will scare other patients with false information.’

(Chemotherapy nurse, workshop)

Some nurses raised concerns they did not feel confident or would ‘feel intimidated with 10–15 patients’ (relatives) (Chemotherapy nurse, workshop) and would require training. Others were concerned by the added workload the group PTCs would generate:

‘Have [you] looked at how tripling the number of patients is going to affect staff workload?’

(Chemotherapy nurse, workshop)

When nurses started to raise questions about practical exercises or some form of testing for patients, the workshop moved naturally into outlining activities and nurse training. Such activities included those that strengthen participants’ coping mechanisms, such as ‘toolboxes’ where relatives are asked to draw objects that help them to cope with cancer and its treatment and share this coping strategy with the rest of the group before placing it in the toolbox.

Discussion

The proposed group PTCs were developed in line with the principles of multi-family groups, a type of family-based psychotherapeutic educational intervention (Simic et al 2021). Multi-family groups facilitate family communication and enhance family resilience and coping with a condition by asking families to identify their strengths and resources to manage challenging issues through a series of carefully chosen familial and group activities (Eisler et al 2016). They have been proven effective in psychiatric settings, for families affected by eating disorders and in those with inherited genetic conditions (Brinchmann and Krvavac 2021, Guerra et al 2023).

The participants in this study recognised that group consultations would not be appropriate for all patients, but they reflected positively on the intervention as a way of involving relatives in the information-giving process, improving recall and empowering relatives and patients to identify adverse treatment reactions and symptoms to enhance health-seeking behaviour. While this intervention is designed primarily for patients to attend with their relatives, attending alone may still be effective because it could assist the individual to draw on personal strengths they have developed through their life experiences.

This study found that some healthcare professionals believed group PTCs might compromise the quality of information delivery for minimal cost-saving benefits for the NHS. However, research shows group consultations reduce time and costs for a service, while maintaining the quality of information delivery (Walming et al 2022). In this cancer service it is expected that the time saved through the delivery of group PTCs will release nurses to spend more time with patients during SACT administration, when patients often require
more individualised reassurance and care to support them with the side effects of treatment.

Finally, while the group PTC proposal was received positively in general, important questions remained about the feasibility and acceptability of delivering group consultations in practice. Challenges include how nurses would be trained in intervention delivery and how to divide groups. Setting group boundaries was also challenging for Eisler et al. (2016) when deciding how families affected by inherited genetic conditions should be divided into multi-family groups. They concluded families did not need to be grouped by inherited genetic conditions, because their psychosocial, emotional and informational needs were similar.

Limitations

The study was conducted at one site, meaning the experiences, views and opinions of the one-to-one PTCs were limited and therefore the study findings might not be generalisable to other areas or populations. Only two relatives were recruited and patients and their relatives were not consulted in the presentation and refinement stage of the intervention development. This has implications for the feasibility and acceptability of the group PTCs for these stakeholders.

Conclusion

The findings of this study indicate that a group PTC intervention was considered promising by patients, relatives and healthcare professionals, although piloting is required to determine its effectiveness and how patients should be grouped. Group PTCs are expected to enhance healthcare professionals’ information delivery and increase patients’ information recall. They may also encourage family-centred care and empower patients and their relatives to undertake positive health-seeking behaviour. Additionally, group PTCs are expected to foster greater use of SACT nurses’ time, so they are more available to provide individualised care during treatment administration when patients typically require more reassurance and one-to-one care. Finally, the implementation of group PTCs and associated training are expected to reduce SACT nurses’ emotional labour.

References


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