Cancer Care Reviews Focus Group  
Thursday 6th December 2018  
10am – 11am

Background

Listening to patients and ensuring their experience and views help to shape the project’s outputs has been key to the Macmillan Primary Care Nursing project from the beginning. Whilst it is well documented that patients’ experience a high level of unmet need following the end of their main hospital treatment and that there is a gap in the supportive care and cancer expertise available in primary care, the project team identified that to their knowledge no attempts had been made to find out from patient what their experience of a cancer care review was like. As our patient partner put it: ‘how do we know that patients find them helpful?’ Attempting to answer this question formed the basis for a focus group, with the expectation that the results would inform the education and influencing strategy for the project.

The findings are outlined below.

Methodology

A Local Enhanced Service (LES) for holistic cancer care reviews (CCRs) is in place in Wandsworth and Richmond. We therefore contacted all GP practice managers from practices within these boroughs who had signed up to the LES via phone or when this was not possible, by email. We asked practices if they would be prepared to identify their last 10 patients who had had a holistic CCR and send out an invitation letter on our behalf. Only 4 practices agreed to do this.

In view of the expected low numbers we worked with the SW London engagement team to review other options. This included developing a survey monkey with the option of joining the focus group at the end, asking two nurses known to the project team to give out paper copies to patients on the stratified prostate pathway, and contacting members of the Voice, a cancer patient forum coordinated by the Macmillan Information Centre at St Georges.

We also used the SW London Twitter feed to publicise the event and each CCG helped promote the opportunity to their local population via social media and their networks.

Results

Four patient representatives signed up to attend the focus group.

Two representatives were from Wandsworth and two representatives were from Croydon.

Other attendees included the project’s patient partner, Sarah Dewhurst (Macmillan Specialist Clinician) as lead facilitator and the SW London engagement manager.

The focus group lasted 55 minutes. The data was recorded with participants’ permission and transcribed verbatim at a later point. Thematic analysis was completed on the transcribed data. Refreshments were provided and each participant was given a £30 gift voucher to recognise the time they had given up (in accordance with NHSE guidance).
Main Findings:

1. There is no sense of handover from hospital to the community other than an awareness of discharge letters; people had not experienced any aspect of the recovery package

“No there wasn’t a notable handover at all. You know it just stopped and then you go in to the next phase which is your appointments”

“No I was just going to say I’ve not seen this (holistic needs assessment) but this would have been really helpful because I can relate to so many things on here”

2. Reaching the end of treatment is difficult and people have a range of unmet needs

“So the physical was being taken care of I felt I continued to have that relationship with the professionals at the hospital the consultants, I couldn’t fault them, absolutely brilliant care but nobody prepared me, nothing prepared me for the psychological effect of going through that trauma and then coming out the other end”

“It was the weirdest thing because you’re suddenly well after being so ill and then you’re sort of cut off from that attention I suppose and being looked after and so you’re suddenly left to kind of get better and just to carry on and I think that was really difficult for me”

“I lost my job as a result of what was happening, I think I’ve got memory loss and, insomnia, all these things, and then because I couldn’t do the things I’d normally be doing before I was diagnosed I was in the gym or I was you know a fitness fanatic I cannot barely walk you know 20m now without stopping and it’s really changed my life and even now there’s so many things I can’t do”

3. There is a sense that the hospital is the place of expertise in relation to cancer and your GP practice ‘doesn’t know what you’ve been through’

“I think the GP didn’t play a part in this at all, the only time I saw my GP was if I made an appointment and the other thing is that they are so busy just to get a regular appointment any way you kind of feel you don’t want to disturb them just to talk to them”

“But then what do they do with the information (discharge letter)? I don’t think they get in contact with me to say oh X we heard you went to A & E last week, how are you? You know, that’s never happened”

“I don’t really try to bother them because I’m still under the hospital as well and so when I see the consultant they can deal with any concerns I have”
4. Vulnerable people might be more likely to struggle if they do not understand the system and cannot ‘shout loud enough’:

“Oh yes because I knew that if I shouted loud enough I could get back to see somebody who’s important who could give me some decisions, unfortunately it’s the people who can’t shout loud enough that I feel sorry for”

“I’m aware there’s a protocol for 2 weeks for cancer so it might be cheating but you know if you feel you want to see the surgeon quickly or somebody who can investigate you can play that card I guess and that’s just being very honest about it”

“It’s fortunate that I’ve got a supportive family and husband and children and they really do support me but for somebody who doesn’t have that and to not have had any of this follow up care you know it would be quite daunting and scary because there are so many things that we could discuss and people might need help with”

Discussion Points

1. Although the focus group was successful it was difficult to recruit to, in part because there is no record of eligible patients so we were reliant on a few helpful practices, and in part because practices were reticent to take part. A few reasons were given by practices unwilling to support our request including being too busy, a belief that people didn’t want a CCR so it wasn’t worth talking to them, patients were already being asked to help with other projects and a couple of practices were not sure whether they’d signed up to that particular LES. During our scoping work we identified a number of barriers to CCRs being undertaken arising from GP practices and this further reinforced the need for this to be explored in a separate piece of work. In addition, the lack of evaluation or record keeping built in to the holistic CCR LES has made targeting relevant patients more complex.

2. The four participants were recruited because they had had a CCR however none of them were aware they had had one. There was no knowledge of any aspect of the recovery package such as a treatment summary which should be the trigger for a holistic CCR and a copy given to the patient; or a holistic needs assessment which ideally would be used to guide the discussion in a CCR. The focus of the group therefore concentrated more on what their experience was like as they finished hospital treatment and what they would have found helpful.

3. More consideration may need to be given to patients’ perspectives and understanding of the role of their GP practice in their long-term cancer management. Although this will happen naturally to some degree if more cancer services are offered in the community, the perception that patient’s need to go back to hospital for any cancer related concerns may take some time to change. Encouragingly the participants spoke highly of their interactions with nurses both at the hospital and at their GP practices and this provides a useful starting point to consider developing general practice nurses’ roles in relation to cancer.
4. We need to share these findings with partners as despite considerable work to promote and imbed the recovery package, the experiences of our participants suggest that there is a long way to go before it is commonplace. The treatment summary should act as a trigger for a holistic CCR and this mechanism might need reviewing.

5. People who are able to attend a focus group are arguably more able than some; the participants highlighted that more vulnerable patients might have a greater level of unmet need and we need to be mindful that this focus group did not capture their views.

Next Steps

- It is crucial to pursue the goal of a focus group with people who are aware they have had a CCR and based on our learning from this process it may be helpful to work more closely with either Wandsworth or Richmond CCG to design a mutually beneficial process; perhaps in sync with the review of the holistic CCR LES

- It was a privilege to hear the stories of the participants and we have some valuable data to use throughout our education and influencing work in the next year. We have also gained consent from the participants to involve them in further work such as our patient story videos.

- Identifying GP attitudes and barriers to CCRs as a separate piece of work has been identified as a recommendation from the wider project

- The findings outlined in this report need to be disseminated to our partners through the steering group

- One patient representative who attended the focus group will be attending an education event to share their experiences with clinicians.