healthwatch
Redcar and Cleveland

Patient and carer experience of cancer care and support both during and post treatment

1. Introduction

1.1 What is Healthwatch?

Local Healthwatches have been set up across England to create a strong, independent consumer champion whose aim is to:

•Strengthen the collective voice of citizens and communities in influencing local health and social care services in order to better meet their needs

and

•Enable people to find the right health and social care services for them by providing appropriate information, advice and signposting.

Healthwatch Redcar & Cleveland works with local people, patients, service users, carers, community groups, organisations, service providers and commissioners to get the best out of local health and social care services.

1.2 Background and rationale

Engagement carried out by Healthwatch staff during autumn of 2013 indicated that there was concern over an unmet need in services for patients who were recovering from cancer treatment. Initial themes that were identified through direct contact and engagement at a Voluntary Sector Forum Event included:

- Lack of care and support in the community for people recovering from cancer.
- Further support required in the community including follow-up appointments closer to home.

Discussion with Macmillan Involvement Workers confirmed that the growth in cancer survivorship in recent years has led to an increase in the number of people requiring follow-up care. National research has previously indicated that follow-up services are not meeting the needs of patients and that routine medical follow-ups and psychosocial support frequently fail to meet the support needs of survivors, resulting in feelings of abandonment during the transition from cancer patient to survivor (Davies & Batehup, 2009). Changing the way cancer survivors are supported, including improving unmet needs, is nationally acknowledged. The National Cancer Survivorship Initiative was implemented in 2007 and was led by the Department of Health and Macmillan Cancer Support, with significant support from NHS Improvement (DH, Macmillan Cancer Support & NHS Improvement, 2013). Locally, in line with delivering care closer to home, South Tees Clinical Commissioning Group intend to deliver more cancer care in the community as part of their commissioning intentions in 2014-15.

Although initial feedback was received from patients and carers within Redcar and Cleveland, experiences from people living across Teesside who access services within the South Tees area have also been included.

2. Methodology

A qualitative mixed methods approach was used to gather patient and carer experience. Questions were proposed, formed from initial feedback, to patients and carers to prompt discussion and elicit responses about their experiences of care and support both during and post treatment (Appendix 1). Patients and carers were also prompted to comment on where there may be gaps in provision or pathways in accessing services.

Although focus was on care and support post treatment, to utilise existing engagement opportunities e.g. support groups, feedback was received on the complete care pathway for cancer patients and is included in this report.

2.1 Engagement with support groups

To gather patient and carer experiences of treatment and discharge, direct engagement was carried out by attending the following:

- Prostate Cancer Support Group (approx. 30 people in attendance)
- Lymphoma Support Group (approx. 10 people in attendance)
- Macmillan Health and Wellbeing Clinic (approx. 15 people engaged)

2.2 Healthwatch Network and social media

A request for patients and carers to share their experiences was promoted by the following:

- Healthwatch newsletter- distributed to approximately 100 organisation members and 60 individual members
- Healthwatch website
- Facebook
- Twitter
- Macmillan Cancer Voices online

3 patients contacted Healthwatch and discussed their experiences in the form of a telephone interview. Prompt questions used for engagement with support groups were also used for the telephone interviews.

3. Key themes

Patient and carer experience gathered from all methods was collated and themed. Individual comments can be read in appendix 2.

3.1 Support and care post treatment

- Ensure consistent awareness and promotion of what is available in the local community to support people upon discharge from treatment and into remission and survivorship. Bridge the gap into local communities.
- Ensure consistent communication between hospital care and GPs during the discharge process. Provide a detailed handover to GPs or relevant agencies/ organisations that can offer ongoing support in the community.

"Communication post discharge could be improved. There needs to be more of a 'handover' to GPs and relevant agencies or organisations who can offer ongoing support. Just because treatment has finished, the journey hasn't"

"All staff were very supportive and details for support groups were given. She met with the dietician and was given information booklets and leaflets"

"I think that hospital staff, doctors and nurses etc should not be afraid to ask remission patients open and honest questions on how the treatment affected them mentally and physically. The answers should be shared with other hospitals. I think that way, things can only improve. I got great treatment but things can always improve in every sphere"

3.2 Experience during treatment

- Ensure consistent communication with patients throughout the treatment pathway regarding the care and support that is available and, what to expect post treatment/surgery, including those people who may receive part of their treatment privately.
- Improve awareness with staff within social services regarding financial support for cancer patients.

"Provide more information after treatment and surgery. A hand-out would have helped me understand why I was feeling like I was- make me feel a bit more 'normal'"

"Although I was under NHS care, I decided to receive chemo privately in my own home and therefore did not receive information about what other support was available for me to access"

"During treatment I had a very good consultant and I had a choice of calling them by their surname or Christian name. It sounds silly but I found that by being on first name terms, it made things easier"

3.3 Prevention and early detection

- Utilise agencies whose 'reach' already involves those groups at risk of developing cancer.

4. Summary

To summarise, patients and carers have indicated a variance in the level of care, support and information that is provided upon discharge from hospital post treatment. It is acknowledged that ‘discharge’ can vary for patients at different stages and many patients require and want different levels of care and support. For example, “*Just because treatment has finished, the journey hasn’t*” and “*As a family we have supported each other and haven’t felt the need to access any support groups*”. However, it was generally expressed that patients and carers would like as much information that is available, to make an informed decision. For example, *“You have to dig to find out”*, *“People are not aware of the Holistic Centre at James Cook Hospital”* and *“There needs to be more of a ‘handover’ to GPs or relevant agencies/organisations who can offer ongoing support”*. During discussions, it was recognised that specialist treatment would not likely be able to be provided out in the community, however, it was expressed that preferably follow-up appointments or consultations could be provided closer to home in the community.

Improving communication post treatment was a prominent theme from engagement with patients and carers and was also highlighted as a key issue for people during the treatment process with health and social care professionals. For example, *“Provide more information after treatment and surgery. A hand-out would have helped me understand why I was feeling like I was- make me feel a bit more normal”* and *“People did not understand how ill level 4 cancer was and were not trained enough to handle my call and my claim for disability allowance”*. However there were many experiences expressed regarding excellent care: *“All staff during referral and treatment were fantastic”* and *“I couldn’t have had better treatment”*.

5. Recommendations

The following recommendations are for those agencies responsible for the provision of care for people suffering with illness due to cancer in our area and also those agencies responsible for increasing awareness to facilitate early access to intervention. These include the South Tees Clinical Commissioning Group, South Tees NHS Foundation Trust and Public Health Redcar and Cleveland. They may also be of interest to those voluntary agencies involved in the provision of care to patients with cancer.

1. Involvement of the local Voluntary Community Sector at the Health and Wellbeing Event

In line with the National Cancer Survivorship Initiative Recovery Package, encourage involvement from local voluntary sector community organisations at the Health and Wellbeing Events that can offer support to individuals and help them with self-management, for example, a healthier lifestyle and increased physical activity. This may include a local walking group or cookery class closer to the person’s community.

2. Support directory

Collate a directory of local support for people receiving treatment and those in remission and survivorship, providing information on what is available in the community to help them whilst undergoing treatment and during the transition from patient to survivor and beyond. This could also be aligned with the National Cancer Survivorship Initiative Recovery Package, in terms of providing details on voluntary community sector organisations that can help people during the transition to supported self-management. The directory could also be given to the patient on discharge, as some of the patients and carers that were spoken to did not attend a Health and Wellbeing Clinic. This information could also be disseminated amongst health professionals such as GPs, as although some patients stated they had been kept informed of available services and support, many expressed they felt that there was a lack of information.

3. Awareness training with health and social care professionals

Ensure that front line staff within social services have an awareness of the severity and levels of cancer and the impact it can have on a person financially and physically who is seeking support.

Consider working in partnership with other agencies who have a reach with particular at risk groups for developing cancer to facilitate early intervention and treatment e.g. organisations working with older people, stop smoking workers or children and family workers in non-affluent areas, to train front line staff about the signs and symptoms to look out for.

Appendix 1

Prompt questions for group and 1:1 engagement.

1. Are you a patient or carer?
2. Are you currently receiving treatment for cancer or are you in remission?
3. What has your experience, at different stages of the cancer care pathway, been like e.g. symptoms, referral, diagnosis, treatment and survivorship?
4. What services have you accessed for treatment and support?
5. Do you feel your needs were met?
6. If in remission, what has your experience been like post cancer treatment?

Appendix 2

4.1 Support and care post treatment

Comments included:

“Sometimes after care and support is available in the community but patients and carers are not always aware. More work needs to be done to bridge care and support into the community upon discharge from treatment”

“The aftercare my mother received from James Cook was fantastic. All staff were very supportive and details for support groups were given. She met with the dietician and was given information booklets and leaflets. As a family we have supported each other and haven’t felt the need to access any support groups”

“Improve promotion of what is available for people to access for support. You have to ‘dig to find out’. The best place to promote after care and support is through GPs and consultants”

“More awareness with cancer nurses and GPs about what is available for patient and carers to support both during and after treatment needs to be improved. People are not aware of the Holistic Centre and James Cook University Hospital”

“Communication post discharge could be improved. There needs to be more of a ‘handover’ to GPs or relevant agencies/ organisations who can offer ongoing support. Just because treatment has finished, the journey hasn’t”

“Utilise support groups to share information with patients and carers both during treatment and post treatment. This can help people understand physiological, psychological and social feelings and help them come to terms with their condition or recovery”

“I think that hospital staff, doctors and nurses etc should not be afraid to ask remission patients open and honest questions on how the treatment affected them mentally and physically. The answers should be shared with other hospitals. I think that way, things can only improve. I got great treatment but things can always improve in every sphere”

3.2 Experience during treatment

Comments included:

“Although I was under NHS care, I decided to receive chemo privately in my own home and therefore did not receive information about what other support was available for me to access”

“All staff during referral and treatment were fantastic”

“After I found a lump I was referred from my GP to James Cook very quickly. The consultant and nurse were very compassionate and informative and I was sent home with lots of literature about the treatment and names of people I could contact if I needed any more information as you don’t take everything in. I took advantage of the

Holistic Centre and had a series of sessions to combat the hot flushes. I chose not to access support groups as I had all the support I needed from family and friends. I couldn't have had better treatment."

"On many occasions I found it difficult dealing with social services regarding claiming money to live on during my cancer treatment. People did not understand how ill level 4 cancer was and were not trained enough to handle the call and my claim for disability allowance. I even got turned down for the council disabled blue parking badge first time I tried to get one- - I had been given a short period to live. People within social services need to understand how cancers and treatments work and how they can affect the body for both financial support and disabled blue parking badge- I had to appeal with a doctors letter of support"

"During treatment I had a very good consultant and I had a choice of calling them by their surname or Christian name. It sounds silly but I found that by being on first name terms, it made things easier"

"More communication through the treatment process e.g. explain why and what is going to happen to help the patient understand"

"Provide more information after treatment and surgery. A hand-out would have helped me understand why I was feeling like I was- make me feel a bit more 'normal'"

3.3 Additional comments on prevention and early detection

Comments included:

"Partnerships with other agencies who have a reach with people who are in the age risk bracket for particular cancers, particularly rural areas, can offer ground support. A project in Northumberland has utilised support care attendants, wellbeing staff and volunteers to train in prostate cancer awareness so they can actively target men and their families to access services"

References

Davies, N. & Batechup, L. (2009). Cancer follow-up: Towards a personalised approach to aftercare services. A review of current practice and selected initiatives. Macmillan Cancer Support.

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