

Supplementary Material

Experiences of colorectal cancer survivors in returning to primary coordinated healthcare following treatment

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INTERVIEW GUIDE – PATIENT VERSION

Introduction

[spoken by interviewer] Once the main treatment for cancer is over, whether it be surgery or chemo-radiation, patients see their cancer specialists less often but some may continue to experience ongoing problems such as irregular bowel movements, pain or difficulty doing usual activities, sexual concerns, even extreme fatigue, among other concerns. We are interested in hearing your views about how any continuing health problems you've had were managed and who helped you with these. We would also like to explore any challenges that you may have experienced in managing these issues, whether you communicated with a GP or other primary care provider, and what has been the role of the GP in ongoing survivorship care.

BACKGROUND INFORMATION

Demographics

- What is your gender?
- What is your age?
- Is English your first language?
- What is your postcode?
- When were you diagnosed with cancer?
- Where was the location of your cancer (colon, rectum, anal)?
- Do you know what stage your cancer was at diagnosis?
- What types of treatment did you receive for your cancer?
- When did you complete treatment?

EXPERIENCE WITH CARE

[Spoken by interviewer]: I would like to ask you about your experience after completing your treatment [surgery/chemotherapy/radiotherapy: *adapt as per the treatment received*]. Try to think back to the time when you completed your main cancer treatment and your cancer specialists said you only needed to see them a few times a year or only if you had a major problem.

Expectation and Preparedness at discharge

1. Did you still have problems from treatment at that time? If so what kinds of problems?
 - a. (possible prompts: what about feeling anxious or fearful, problems sleeping, getting things done, stress, pain, problems with peeing or pooing, sexual problems, anything like that?)
 - b. Do you still have any of those problems or has anything new been a problem for you since then?
 - c. How would you describe the severity of these problems? (e.g. mild/minor – serious/major)
2. Since completing your main treatment, have you experienced anything unexpected or surprising as a result of your treatment?
3. In general, if you experienced any symptoms or other concerns who would you contact first? Why? (possible prompts: Did you see anyone for help with these problems? Did you discuss them with your GP? Did your GP ask or did you bring them up?)
4. How do you decide who to go to?

5. Are there any reasons why you did not/might not get help for any of these concerns? (possible prompts: considered minor, thought I just had to live with it)
6. Were you aware of possible issues that might occur because of your treatment? e.g. pain, fatigue (*prompt with examples: pain, fatigue, emotional, fear of recurrence, sexual, physical*)?
7. Were you told who to contact if you experienced any symptoms or other concerns?
8. I would like to explore with you the use of medical language. Sometimes we think we use everyday language to describe symptoms and side effects but actually these terms might not be everyday language easily understood by non-medical people, for example, 'incontinence' or 'opening bowels'. Did you have any difficulty understanding any of the terms or words communicated to you by any health professional after completing treatment?
 - a. Can you tell me more about that – which terms?
9. Prior to your cancer diagnosis, did you have a regular GP or GP practice you saw for things like health checks, tests or other issues?
 - a. Do you still see the same GP (or general practice)?

Interactions with GP

[spoken by interviewer] In the next lot of questions, we would like to know about GPs involvement in providing care for people after they have completed their main cancer treatment.

10. During your cancer treatment, did you see your GP?
 - a. If so, what was the purpose of the visit?
 - b. Did you discuss your cancer and any issues you were having?
 - c. Was your GP able to help or support you with those problems?
11. Since completing treatment, have you seen your GP or visited your general practice for any CRC treatment related concerns?
 - a. If not seen a GP, answer Qs 8-14, then go to Q 18
 - b. If yes, go to Q15
12. Is that because since completing treatment you have not experienced any symptoms or other concerns relating to your cancer treatment?
 - c. If some other reason, what were your reasons for not seeing your GP for help with these concerns? [prompt with 'Can you tell me more about that?']
13. Are there other health professionals that you saw for any CRC treatment related concerns?
14. Have you tried to access any services or other methods to help with the issues or concerns you experienced?
 - d. If so, what services or other methods did you try?
 - e. Were you able to easily access those services?
15. What were the reasons you needed to see your GP or other primary care provider since completing your main treatment? (example prompts: routine cancer-related follow-up, help with managing symptoms/treatment effects, need for referral to specialist services, managing other illnesses etc)?
 - a. Have you needed to see your GP for help with managing any symptoms or other concerns related to your cancer treatment specifically? (possible prompt: imagine you had problems with stress or other emotions, pain, or sexual or pooing problems, would you see a doctor or someone else?)
16. If you saw your GP for other reasons, did your GP ask specifically about recovery and how you are managing any symptoms from treatment?
 - a. If yes, did they ask the right questions? Did they ask you about all of your issues or just some of them?
 - b. If no, did you raise your problem with them? Why or why not?
17. Do you expect your GP to ask you about any possible issues like sexual problems, stress, pooing, pain or anything else that might be a result of cancer treatment?

18. Were there any concerns related to your cancer treatment that you found difficult or unable to raise with your GP? If yes,
- What were these concerns?
 - What were the reasons that you did not raise these concerns? [*explore why info was not disclosed/discussed, example prompts: too sensitive/personal, because of GP gender, felt embarrassed, felt uncomfortable discussing certain things, lacked confidence in GP, GP personality, did not know how to bring up with GP, others, for example, bowel symptoms, sexual issues, difficulty coping, because of how GP interacted with me*)]

Experience with managing problems and treatment for CRC [Only if answered YES to Q10]

19. Overall, do you feel that your GP had a good understanding of the possible symptoms and other issues that could be experienced after having treatment for CRC?
20. What support did your GP provide you for managing concerns relating to your cancer treatment? (for example, referral to acute care, use of investigations (pathology, radiology), prescribing of medications, opioids, antidepressants) (possible prompt: were they able to help or refer you to someone for appropriate help? These concerns can be broad such as diarrhoea, fatigue, fear of recurrence, family relationship, sexual etc.)
- Do you think GPs could do more or be more involved?
21. Did your GP help you directly or refer you to someone to help you with the concerns that you had?
- If no, what could they have done better or differently?
 - If yes, what was most helpful/useful? [*example prompts: provided medical advice, medical intervention*]
22. How has your CRC experience impacted upon your other health and wellbeing issues?
- Has your GP been able to help you manage/balance the various issues?
23. Was your GP aware of available services, resources or other health professionals within the local community that could help address your specific concerns and needs?
- If yes, What sources of information or advice that you received did you find helpful?
 - If not through your GP, how else have you managed any symptoms of other cancer treatment related concerns that you experienced?

GP ROLE AND AREAS FOR IMPROVEMENT

24. Do you think the GP should be the main healthcare provider who coordinates your follow-up care after cancer treatment?
- If no, why? Who else should be the main healthcare provider who co-ordinates your ongoing care after completing your main treatment?
 - If yes, why do you think this?
25. Do you have any advice about how we could ensure adequate support and improve the ongoing care for CRC survivors in the community?
- What would have helped you to have better care?
26. Ideally, what could GPs do differently to provide adequate supportive care for CRC patients?
27. What could cancer specialist services do differently at discharge from hospital, for example, after surgery, to enable better supportive care for CRC survivors by their GPs?
28. Ideally, how can we best monitor and manage long term effects of CRC treatment?
29. What have you learnt from your experience that would help other cancer survivors' recovery from treatment?

[Spoken by interviewer] Thank you for answering all of my questions. Do you have any additional comments to make about anything that we've discussed today?

Thank you for your time today.