



BCCC

Better Consultations in Cancer Care

PATIENT CONSULTATIONS A Guide for Doctors



**University of
Leicester**

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NHS Trust

“A lot of what is in the booklet is what we already do, but it is just keeping it fine tuned and I think you do need constant feedback. The main points are very important and pertinent. The booklet is something you can use to refer back to maybe every 3 or 4 months or if you have had a bad consultation you might want to refer to it to see what you could have done differently.”

Consultant Oncologist

The comments inside this booklet were all made by patients we interviewed

Acknowledgments

Our grateful thanks to the patients who gave their time to talk about their consultation experience.

We also thank the doctors who gave their thoughts, to help us understand the consultation process from their perspective.

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“ This booklet is useful for doctors as it highlights what we might be doing right or wrong. It reminds us of the things we need to do in the consultation and it also reminds us that we need to see things from the patient's point of view. So it is really useful. ”

Specialist Registrar

Introduction

The information presented in this booklet is based on research evidence from detailed analysis of audio recordings of consultations as well as interviews with doctors and patients.

The way patients respond to the diagnosis of cancer is very personal. Many patients tell us that the complex emotions and pressures they face have a negative impact on the way they are able to cope and adapt to what is happening to them and may interfere with the way they are able to:

- Process and understand information
- Think clearly about what it is they want to know
- Make decisions

One of the issues doctors faced was knowing whether or not the information they disclosed to patients about diagnosis, prognosis and treatments was wanted or understood. This uncertainty was complicated further if they did not know what colleagues had disclosed in previous consultations. Data from our research has been used to develop a consultation aid for doctors and patients to use together to improve communication in patient consultations, in terms of accuracy, timeliness and sensitivity of patient needs.

This booklet forms the companion to the patient booklet. The aim of the booklet is to provide you with some useful information from doctors and patients accounts of their consultation experiences. We hope that this information might act as a reminder of what needs to be achieved within the consultation to improve the experience for all.

From the evidence we have generated the focus of the consultation should be on **enquiring** rather than **telling** or **assuming** what it is we think patients should or should not know.

Consultation Guide

Prior to their new case consultation, patients will be given an information pack which will include:

- The patients version of this booklet
 - Consultation aid leaflets
- (to be used in conjunction with new and follow up consultations)

In the booklet patients are given information which:

- Describes the treatment pathway
- Lets them know what to expect in new and follow up consultations
- Answers some of the more general questions and concerns patients have about the consultation process
- Provides information to help them think about what they want from their consultation

In the accompanying leaflet patients will be able to write down:

- Any questions or concerns they have
- What they **would** or **would not like** to know
- What is important to them right now
- Whether or not they are able to think about making decisions
- How they would like you to disclose information to them

The patient will complete the leaflet prior to their new case consultation and on subsequent follow up consultations (when they choose to use them).

The leaflet will be handed to the clinic co-ordinator who will put this on the front of the patients notes. You can read this leaflet before seeing the patient so that you know what their thoughts are and can tailor the consultation to meet their needs. Should the patient change their mind while waiting to see you, it may be necessary to check that the information they have provided is still correct. The leaflet can then be handed back to the patient at the end of the consultation.

We do not envisage that the use of this leaflet will further impinge on your time. Patients are advised that time is limited within the consultation and they need to appreciate that not all their needs may be met within one consultation. However, patients are generally very conscious of time and thoughtful of taking up too much of your time and delaying the wait further for other patients.



“ A patient told me that when she was first diagnosed and was told she'd got to have chemotherapy, she asked 'Am I going to lose my hair?' Her consultant said 'Oh, you women. All you worry about is losing your hair' it's such a throw-away comment he probably can't even remember saying it, but it really upset the patient for months. ”



“ I don't think any of the doctors I have interacted with have actually shown me much warmth and that would have made such a difference to me personally. ”

Ways to Improve the Consultation Experience

Preparing for the consultation

Two main issues were significantly important to patients in regards to the preparation of their consultation – one of which was also reflected in doctors' accounts.

The **first** issue related to continuity. For some, continuity meant seeing the same doctor for each consultation. For others, this was less important, as long as they felt the doctor had taken the time to read through the relevant sections of their notes prior to seeing them. If they believed the doctor knew something about them, this was seen as a sign of respect. Patients were unhappy if they felt the doctor had not read their notes.

It was also considered to be inappropriate and rude to read their medical notes in front of them.

The **second** issue concerns insufficient information. On occasion relevant information such as test results were missing from patients' medical notes. Consequently, some doctors described the difficulty they had in managing a consultation if they did not have relevant reports to make clinical decisions. For patients, when all the information was not available they felt that the consultation was a waste of their time. In the event that a report is unavailable, it is best to be honest with the patient about this. While they may not be happy, they are more likely to respect your honesty and trust you in the future. Most said they would prefer to have a consultation postponed rather than have a wasted visit to the hospital.

“I’ve always felt like she was doing her best to get me better. I wasn’t just one of her many patients; she was doing everything in her power to get me better. She was perfectly honest with me about it all. And so because she was honest with me I just felt like she cared as well.”

Interpersonal styles

Our data shows it is important to be aware of your personal interactions with patients and any companion (s) and reflect on how you might be perceived by others.

For example, some patients felt that their doctors were unable to demonstrate empathy and acknowledge what a difficult and emotionally challenging time they are going through. It was unhelpful if:

- Throw away comments were used which trivialised their situation.
- The doctor appeared blasé and failed to offer hope – in effect closing the door on them.
- The doctor didn’t have time for them (this does not mean length of time, but a feeling of being rushed).

Patients want to be treated as individuals and want to be respected as fellow human beings. To help achieve this patients appreciated it if their doctor:

- Listened to them.
- Didn’t dismiss what they had to say.
- Were friendly, calm, compassionate, thoughtful and honest.
- Told them they would do their best for them.

If you are aware that a patient is upset and you are aware that you are blocking this, you need to reflect on the reason why you are blocking them. If it is related to time, then a couple of extra minutes could have a major impact on the patient and their wellbeing.

If it is because you are concerned that you don’t know how to deal with emotions then there are others who can, so be honest and refer the patient to the appropriate person – **Don’t ignore them. It is part of your role to acknowledge emotional distress and try and help in some way.** By doing so you might find out some very important and relevant information from your patient.

Some of what we address in this booklet is basic advice captured from multiple perspectives with a view to creating context sensitive guidance on communication practices. The research has shown that there is a need to go back to basic communication practices with a clear focus on the patient. This booklet will be followed up with an educational supplement providing further guidance on the issues covered.



Information need and expectations

A patient's need for information may change throughout their illness. Our data shows it is important to remember that information does not need to be given at once and patient's can receive information as and when they are ready to listen to it. This is why it is important to enquire rather than simply tell or assume what you think they should hear.

If patients are given information when they are not ready to hear it and / or feel that the doctor has given them information in a 'brutal' and 'insensitive' manner, this will upset them and have a knock on effect for future consultations which become difficult to resolve. If you encounter this with your patients, you can try and improve the situation by:

- Being sympathetic
- Listening to what they have to say
- Acknowledging how difficult the previous consultation has been for them
- Apologising

For patients, it is extremely important to cushion what you have to say to them with hope. It is important for patients to know that there is some hope and that they will continue to receive support; if not by you, then by someone else. It is also important for them to know that they can contact the Oncology department, even if they have completed treatment and are being seen in follow up. From what they have told us they are unlikely to take advantage of this as they appreciate how busy the department is.

“If you have too much too soon you can't deal with it'. If I'd known things might change at the beginning, I think my brain would have exploded; I couldn't deal with it.”

“You need to take it one stage at a time. You need all the information for that stage and then you can move on to the next bit.”

One of the main problems doctors described facing, was knowing how to share prognostic information with patients. From what we have learnt, you need to be prepared to answer questions related to prognosis, following these simple guidelines:

- Check with the patient that they want to know.
- Start by answering the question broadly and invite them to ask for more information if they want it and then you can respond to their request if you can.
- You might consider starting by directing the question back to the patient and ask them what they think, particularly if their life expectancy is limited.
- Don't be brutal.
- Don't be too abstract.
- Don't give false or misleading expectations.
- Be honest and sensitive. If you really don't know what to say then say so.
- Give a more open time frame rather than being too specific.
- Try to combine realism with optimism

Although, you might think some of these points are obvious, we noticed a number of problems associated with prognostic discussions. Always tailor your explanations towards the patient's level of understanding. For example, some patients really did not understand what the terms radiotherapy meant or what consecutive days of treatment meant but they will not necessarily tell you this for fear of looking stupid.



Facilitating the opportunity to ask questions

Some patients will not ask you questions, despite having a list of them prepared because they are trying to be a 'good patient' and not take up too much of your time. They then fail to meet their own needs within the consultation and go home with some dissatisfaction. A situation needs to be created where patients feel they can ask their questions. It is not always appropriate to ask them at the end of the consultation. You might need to ask them at various stages throughout the consultation and / or leave pauses in the conversation at appropriate times.

Patient involvement in the decision making process

When it comes to making decisions, patients often feel ill equipped to do so, as they do not have the necessary knowledge and expertise to know which treatment is best.

Some patients want to be more involved in the decision process than others. Most of the patients wanted the doctor to find out about their personal situation and preferences and wanted the doctor to tailor the advice according to those preferences. True 'patient-centredness' is not about handing over the decision making to patients and insisting they make the choices. It is about finding out what sort of role they want to take and responding to them as an individual.



“When they said you know you’ve got cancer, you can have chemo. If you want it, it is your decision, it was really hard to decide. I asked ‘what would you do?’ and they said ‘well I can’t tell you that, you’ve got to make the decision for yourself.’ It was really hard.”

“You’re just made to feel part of it and I am the biggest part of it aren’t I? I’m allowed to put my own point of view in; it’s digested and then a response comes back. I am having a conversation with someone. I have not experienced that before and I trust him.”

In creating this booklet we hope that this information acts as a reminder on what we should be considering when meeting our patients and sharing information with them.

We hope the consultation leaflets will help your patients communicate their needs to you more clearly and allow you to respond to them in the manner that they wish in order to improve patient satisfaction.

If you have any suggestions on how to improve the booklet, contact:



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