

You were telling before that... How was it with...? How did you feel when XY happened...?	Can you tell me a bit more about that? How did you experience...? What was done there exactly?	Do you remember any situation in which...? And then, how did it proceed...? How would you have liked it to be?
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Interview Guideline – Colorectal Cancer . Translated from German by Authors

Themes	Themes abstract	In-depth questions	Notes
Opening question to start narration	Maybe you can start by talking about how your life was when you first became aware of the signs of colorectal cancer and how it went from there. Take your time and talk about how one thing led to another.		
How one thing led to another...	<ul style="list-style-type: none"> • First signs • Consultations with doctors 	<ul style="list-style-type: none"> • When did you feel suspicious for the first time? Did you feel anxious? • Why did you consult a doctor? <ul style="list-style-type: none"> • Do you remember...? • What made you take this decision? • Were you alone or was somebody with you? 	
Diagnosis	<ul style="list-style-type: none"> • Tests / diagnosis / second opinion / receiving information and explanations <ul style="list-style-type: none"> ○ Faecal occult blood test ○ Palpation examination ○ Colonoscopy ○ Partial colonoscopy ○ Blood examination ○ Ultrasound ○ CT scan ○ MRT scan ○ PET scan 	<ul style="list-style-type: none"> • How were you diagnosed? • How did you feel about it? • What was done during XY...? <ul style="list-style-type: none"> • Why was it done? • How did you feel about that? • Did you have pain? 	
Preventive medical check-ups	<ul style="list-style-type: none"> • Preventive medical check-ups 	<ul style="list-style-type: none"> • Did you take part in preventive medical check-ups? <ul style="list-style-type: none"> • Why yes / why no? • How was that for you? 	
Second opinion	<ul style="list-style-type: none"> • Second opinion <ul style="list-style-type: none"> ○ Who mentioned it? ○ What was the reaction? 	<ul style="list-style-type: none"> • Did you get a second opinion? <ul style="list-style-type: none"> • What were your experiences of that? • Was it recommended by the doctor? 	

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Cancer in the family	<ul style="list-style-type: none"> Colorectal cancer in the family 	<ul style="list-style-type: none"> Are there any cases of colorectal cancer in the family? Was it talked about before you got colorectal cancer yourself? Did it have an influence on your medical check-ups? 	

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<p>Receiving information and explanations</p>	<ul style="list-style-type: none"> • Receiving information about examinations, therapies • Relatives 	<ul style="list-style-type: none"> • Did you feel informed before the examinations? • Did you receive all the information that you needed? • Would you say afterwards that information was missing? • Were you alone or was somebody with you? • Did the doctors talk to your relatives? <ul style="list-style-type: none"> ○ Were you present? 	
<p>Disease stage</p>	<ul style="list-style-type: none"> • Current disease stage 	<ul style="list-style-type: none"> • Disease stage – what do you know about it? <ul style="list-style-type: none"> ○ Disease stage at diagnosis? ○ Recurrences / metastases / prognosis? ○ Colorectal cancer in the family? 	
<p>Treatment, therapies</p>	<ul style="list-style-type: none"> • Decision-making • Information • Treatment plan • Operation • Chemotherapy • Radiation therapy • Immune- / antibody therapy • Other intervention (Port, ascites puncture, etc.) 	<ul style="list-style-type: none"> • How and with whom did you take decisions about which therapies to choose? • How informed did you feel before the examination? <ul style="list-style-type: none"> ○ Did you receive all the information that you needed? ○ Would you say that some information was missing? ○ Were you alone or was somebody with you? ○ Did the doctors talk to your relatives? <ul style="list-style-type: none"> ▪ Were you present? • What did the treatment plan include? • How did you experience therapy XY? <ul style="list-style-type: none"> ○ How did you feel when ... ? ○ What was done exactly? ○ Did you experience any pain? ○ Were you conscious or did you get an anaesthesia? ○ Were you alone during the therapy? Who was with you? 	

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	<ul style="list-style-type: none"> • Pain therapy • Medicine compatibility and side-effects • Supportive therapy <ul style="list-style-type: none"> ○ Nausea & vomiting ○ Diarrhoea ○ Mucosa irritation ○ Bleeding / anaemia / infections (due to changes in blood count) ○ Fatigue ○ Weight loss • Medication intake • Participation in a clinical trial 	<ul style="list-style-type: none"> ○ Specific information concerning therapy XY. ○ Were there any waiting times? How did you experience these? • What was the most unpleasant thing? • How was your pain treated? • What were your experiences concerning pain therapy? • Which side-effects did therapy XY have? <ul style="list-style-type: none"> ○ What helped you to deal with it? Were you informed about it beforehand? ○ How long did the side-effects last? • Did you have other symptoms during the cancer disease? <ul style="list-style-type: none"> ○ What helped you deal with it? • Do you take medicines regularly? <ul style="list-style-type: none"> ○ Which ones? ○ Do you have experiences with side-effects? ○ How do you deal with this? ○ What helps you? • Did you take part in a clinical trial? • Who initiated the trial / who conducted the trial? • Were you actively searching for a clinical trial? • How was your experience? How did it take place?

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	<ul style="list-style-type: none"> • Complementary / alternative treatment methods • Setting 	<ul style="list-style-type: none"> • Do you have experience with any other treatment methods (for example, mistletoe therapy, vitamin products, selenium, diets, etc.)? • Did you talk about it with your doctor? • Where did you get treated? (hospital or from home...) • How did the practitioners of the different institutions work together? • How did you get into the clinic? 	

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Stoma	<ul style="list-style-type: none"> • Stoma • Handling of stoma • Impact on daily life • Incontinency <ul style="list-style-type: none"> ○ Urinary incontinency ○ Faecal incontinency <p>(Colostomy, Ileostomy, Urostomy)</p>	<ul style="list-style-type: none"> • Did you get a stoma during the treatment? • How did it come to this? How did it take place? • How did you experience it? <ul style="list-style-type: none"> ○ What type of stoma? ○ Permanent stoma? ○ How and from whom did you learn to handle the stoma? ○ What was your experience?
Doctors	<p>What were your experiences with doctors or therapists? Are there specific situations that you remember?</p>	<ul style="list-style-type: none"> • What were your experiences with doctors or therapists? • Were you in contact with other patients? • Which doctors do you consult? • What do you talk about with doctors? • Do you prepare for doctor appointments? <ul style="list-style-type: none"> ○ How? ○ Do you go alone or does someone go with you? • When it comes to treatment decisions, who is included in decision making? • Are you receiving the information that you need? <ul style="list-style-type: none"> ○ How do you seek this information? • Are you thinking of changing doctor? • Do you remember any situation that you experienced as uncomfortable or helpful?
Institutions	<ul style="list-style-type: none"> • Patientnavigation • Experiences with acute care clinics, GPs, rehabilitation clinics, etc. • Temporary care at home (transition from hospital to ambulatory care), other care at home 	<ul style="list-style-type: none"> • Do you have any experiences with patient navigators? • How were the different institutions connected to each other? • Were there any problems? What turned out to be helpful? • Were there any specific people in the institution that were particularly important /helpful for you? • How was the organisation afterwards?

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	<ul style="list-style-type: none"> • Psycho-oncology 	<ul style="list-style-type: none"> • Did you attend occupational rehabilitation? <ul style="list-style-type: none"> ○ What experiences did you have? 	
Follow-up care?	<ul style="list-style-type: none"> • Follow-up care – how often? • What is done? 	<ul style="list-style-type: none"> • Are you attending any follow-up care? • How often are you doing examinations? 	
Authorities, social help and patient rights	<ul style="list-style-type: none"> • Experiences with payers and authorities • Finances • Sickness benefits, occupational disability and incapacity to work • Retirement, temporary retirement • Care level • Medical aids • Disabled person's pass 	<ul style="list-style-type: none"> • What are your experiences with health insurances / pension fund? • Did the cancer have a financial impact on you? • How and from whom did you receive support? • Are/were you receiving a pension? How did it come to this? With whom did you discuss this? • Are you assigned to a particular care level? <ul style="list-style-type: none"> ○ Who helped in putting in the claim ○ Was it approved? • Do you have a disabled person's pass? <ul style="list-style-type: none"> ○ Did you claim it or did you have help from someone? ○ Was it approved? 	
Information	<ul style="list-style-type: none"> • Experience with self-help groups • Sources of information • Experiences with the Internet 	<ul style="list-style-type: none"> • Do you have any experiences with self-help groups? If yes, which ones? If no, why not? • What information did you get after receiving the diagnosis? Where from? • How did you inform yourself when taking a particular decision? • Did you inform yourself using specific guidelines / Internet sources? <ul style="list-style-type: none"> ○ How and where was this successful for you? • While reading websites/books, were you scared? • Are there situations when you consider informing or not informing others? 	

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	<ul style="list-style-type: none"> • Personal Information policy: Hopes and fears of informing others 	<ul style="list-style-type: none"> • How do you decide whom to tell about your illness? 	

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<p>Job, daily life, leisure time</p>	<ul style="list-style-type: none"> • Impact on the job • Impact on daily life • Circle of friends • Final impact • Impact on personal Independence • Psychological impact 	<ul style="list-style-type: none"> • Are you working? What do you do? How long? Did you change anything about your job? How did your colleagues/boss react? • What impact does the cancer illness have on your daily life? <ul style="list-style-type: none"> ○ Did you have any kind of support during the therapy at home? (household help, taxi, etc.?) • Are there any hobbies that you still do / cannot do anymore? • Does the illness have any impact on your nutrition? • How do your friends deal with the illness? • With whom do you talk about the illness? • How independent are you? • Was life during (chemo/radiation, etc.) different? • Does the cancer have any influence of your mood, psychological well-being? <ul style="list-style-type: none"> ○ Bad days: are there any fears, desperations? How do you handle these? Not wanting to go on? ○ Psychological / psycho-oncological treatment? 	
<p>Confrontation with end of life</p>	<ul style="list-style-type: none"> • Living will and power of attorney • Ideas, hopes, attitudes • Active euthanasia/suicide • Experiences with communication about death and dying 	<ul style="list-style-type: none"> • Do you have a living will? • Have you assigned someone power of attorney? <ul style="list-style-type: none"> ○ Was that ever relevant for you? Who worked on that with you? How was that for you? • Thoughts about active euthanasia/suicide? • Was that relevant for you during the course of the illness? • Ideas about life after death? 	

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Personal thoughts/ideas	<ul style="list-style-type: none"> • General questions about type of burden, support • What helped you? • Resources • Subjective theories about illness • Sense, beliefs, coping • Looking back on life • Meaning 	<ul style="list-style-type: none"> • What challenges did you experience in your life due to cancer? • Did your life change because of it? • Do you have the impression that you have changed as a person? • What characteristics or abilities help you most in coping? • Who supported you in particular? • What was or is the biggest support? • Do you ask yourself sometimes: Why me? Does having the illness make any sense to you? • Does belief / spirituality / religion have a meaning for you? • Did you find support in religious or other spiritual sources? • When you think back, is there something that you would do differently today? • What does colorectal cancer mean for you? 	
What helped? Finding sense / questions	<ul style="list-style-type: none"> • Literature, media, etc. • Resources • Worries 	<ul style="list-style-type: none"> • Were there any books that helped you? • Were there any films that helped you? • Political views • Were you scared when reading websites / books / watching movies? 	
Quality of life	<ul style="list-style-type: none"> • Quality of life 	<ul style="list-style-type: none"> • Quality of life – what does it mean for you? 	
Closing questions	<ul style="list-style-type: none"> • Wishes for the future • Messages to other patients • Messages to doctors • Other topics that were not covered 	<ul style="list-style-type: none"> • What are your wishes for the future? • Is there anything you still would like to try out? <ul style="list-style-type: none"> ○ Did this change due to the cancer illness? • Do you have a message to other patients? • Do you have a message to doctors? • Is there anything of importance to you, that we didn't speak about yet? 	

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