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Reflecting on a case of a “difficult patient” with paraplegia and severe tenesmoid pain. What can we learn out of this?

Abstract

In this article I describe a “difficult patient”. An intelligent man, who became a cripple because of “benign” tumour of his spine. He became a paraplegic and became very much dependent of his wife and of us. He behaved awfully and nobody liked to help him. He sensed this. I analyse the psychology of this. He manipulated himself in the position of the victim to attract our attention. In fact he was doing the opposite. I also reflect on our own resources, how the team survives such a patient. A long, but fascinating story, I would never like to miss in my career.

Key words: ependymoma, rectal pain, neuropathic pain, acceptance, dealing with “difficult patients”, opioids

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Introduction

I am working as a consultant in palliative medicine in a large hospice in Switzerland. In hospice I run a “Trouble shooting” Clinic for the community patients. Sometimes I write some notes to reflect on them later. Sometimes, like now, after two years, I find them again and start to think. I know of course what happened next, after I became exhausted and stopped writing in my diary. However, this kind of notes are a very good learning tool.

Medical history and current complaints

Peter is 62 years old. Previous medical history unremarkable. Seven years ago after a short period

of leg weakness and excruciating pain he was diagnosed to have spinal cord ependymoma. He was treated with surgery and radiotherapy. Since the operation Peter suffers paraplegia and experiences a lot of pain in the lower, anaesthetized body half. This pain is shooting and worse on movements. A separate quality of pain is experienced by him in his rectum (tenesmoid pain) and this pain is preoccupying him. Although the shooting pain is amenable to therapy, his tenesmoid pain and urge to defecate are not. He persuaded the surgeon to establish a defunctional ileostomy. This operation did not change much in Peter’s perception of pain, but made him more dependent on others and more disappointed. Peter is using high doses of different drugs against the pain.

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Psychosocial background

Previously to his disease and disability Peter was running a small business and was used to be a manager. He is married to Angela and they have two adult and married children. The disease, suddenly, ruined all the family life. Peter became a grumpy, continuously complaining and unpleasant man. The children have a lot of conflicts with their father; especially the in-laws could not cope with the situation. Peter's oldest son said recently that they will never bring their children with them again as they are afraid for their psychological health. Angela is a quiet and introvert woman, doing for a long time her best to take care of Peter and to please him. She is carrying her cross with love and dignity. However she is now at the edge of burnout. She just can not cope with the situation any more. She is very ambivalent about Peter, somehow she wants to keep carrying for him, on the other side she knows that this will bring a lot of drama and this will be at her cost. Sometimes she wishes Peter would be admitted to the nursing home. Peter however, is very angry on her, because of this. A time ago Angela had sinusitis. This usually trivial disease knocked her down for several weeks and Peter needed to be admitted to the hospice, until she would recover. Peter said that she is making this up and he does not believe her she was that ill.

Admission 1

This admission was in principle for respite, because of Angela's sinusitis. I sensed that the couple needs more than only respite and I started to review Peter's history and medication. In the beginning Peter did not trust me at all. He did not want to change anything in his medication. He was denying he has the neuropathic pain in the spine, his problem were the bowels. He insisted on bowel washing with water which in our eyes were ineffective. During this admission I saw that Peters' behaviour is disruptive to the surrounding. There is no good communication between the patient and the doctors and the nurses. Also other patients in his room are getting upset. Nurses are taking a big breath before entering this room. Family is happy Peter is in Hospice and they distance them from Peter and are coming only infrequently, if ever. I saw also that Peter is manipulating his surrounding. He takes medicines as he likes them. He is, not really listening to us, and we are probably not listening to him. He was taking slow release carbamazepine orally, but the tablets were

appearing 20–30 minutes later in the ileostomy bag. I told him the drugs are probably not doing any good. He insisted, that they are the only effective drugs he is taking. When I finally managed to change them to immediately release carbamazepine and tried to titrate the dose up, he immediately got a headache with the lowest dose prescribed. Peter left hospice after 4 weeks and we all hoped he will not come back for a while.

Admission 2

Peter was 8 weeks at home. At certain moment we were alarmed by dramatic increase of tenesmoid pain and we admitted him to the bedded unit. Peter told us that after a bowel wash (first in two month) he found something in his faeces which looked like a cover to the Predfoam which he was getting at home rectally long time ago. After this cover/plug was born Peter's pain increased dramatically. There was also some rectal blood discharge. The dose of fentanyl was increased from 300 to 375 mcg/hour and the dose of Oramorph increased from steady 100–200 mg/day to 1200 mg/day. All of this without result. So, when Peter came back for this admission I was decided to be more directive and to take the steering wheel more in my own hands. I had several long sessions with Peter and tried to have a separate session with Angela, but Peter made this meeting impossible.

I advised Peter to undergo sigmoidoscopy. He refused this. I expected him to have proctitis which is sometimes seen in paraplegics [1]. This proctitis could be exacerbated by *corpus alienum* like a cover of the applicator which was accidentally "injected" into his rectum. After long consideration we decided to treat proctitis with daily enemas.

He improved considerably and we could discharge him home again. Just before the discharge nurse detected in his night table plenty of different medicines Peter was taking without informing us about this. Among them were morphine tablets and... slow release carbamazepine tablets. When confronted with this he said all of them were prescribed by the neurosurgeon and we should know this from him.

Peter went home again and the first feed backs were very positive. The pain was less, he was not using the breakthrough doses at all. He was joyful and more pleasant for his surrounding. However, if things are going better, the need to go wrong one time. After one application of the enema, Peter started to experience horrifying pain in

his rectum/anus. He accused the nurse she perforated his rectum. Drama started all over again.

The GP was asked to see Peter at home, but was not aloud to examine him, because of pain. Peter told the GP that I made a mistake and started therapy without doing first the sigmoidocopy...

When Peter tried to get admitted to hospice again I insisted he will go first to the hospital for the proper diagnosis. He became admitted there, but again, refused the sigmoidoscopy and was discharged home.

All of the time I was concerned with Angela. She was of high risk of morbidity and even mortality. However, she was more or less shielded by Peter and I was not allowed to contact her.

My reflection

"Difficult patients" do not exist. I still believe in this. There are only patients with difficult coping mechanism and a lot of fear and distress. All of this is usually not very problematic in malignant cancers where the terminal illness is usually limited to several months. In Peter's case we are talking about years behind us, and years to come. Ependymoma is, histologically seen, a benign tumour. But benign tumours may be more problematic than malignant one. We only rarely realise this. I am sure many of us, including hospital consultants, nurses and social workers, me personally too, were praying that Peter's tumour progress and he would start to behave like a decent terminally ill patient.

On the one side palliative care asks a lot of involvement and less distance between the patient and the carer. On the other side our involvement must be limited and the borders should be clear to everyone involved. In the past I learned from my pragmatic colleagues in Holland, that this patient "does not allow" to help him. Some colleagues even have said that such patient "does not really want our help". Peter manipulated himself in the position of the victim and wants to keep this position attracting attention and care of the others but enjoying kind of power. For a disabled person this may be an important strategy to survive. I think we should be actively involved and we should always try to help. Can we ever say "No, I am sorry I can not help you?" This dilemma keeps me busy for many years. I think I usually try to go further than others, but I need also to keep myself and my psyche in a good shape to be able to help others and not to be drawn myself.

Patients like Peter are not very common. Thanks God. But when they appear on your books (and in contrary to other patients, their GPS

and consultants are very keen to refer them to you) they may claim much of your time and attention and you will run short of it facing other patients. And you may even feel guilty that you are irritated or tired, that you forgot things and messed them up. Not to mention your wife and family life.

Peters' case was a good opportunity to me to see how the team is responding to a stressful situation. Some staff members and this you see everywhere in palliative care, just believe they can change the world and believe that bad should be answered with good. Whatever happens. These people go quite far in their involvement but take big risk. They are in a natural conflict with others who immediately wants to distance from such a patient. They do not say this directly, but say: "this patient does not belong here", "he would be better off in a nursing home", "he should be elsewhere" (this is why some people are keen to refer these patients elsewhere), "he is not benefiting enough from our efforts" and "we make him dependent". So people who take a big breath before entering patient's room are all professionals, but also human beings with different views, attitudes and passions.

Despite my respectable age and experience I belong to the group who enthusiastically welcomes "difficult patients" and tries to "change the world". So, how on earth do I survive this mess? I believe in what I know and what I can instantly learn. To be honest, I find myself also naïve and vulnerable. And every time when I confront patients like Peter, after a while, there is a small crisis in me. I bounce from the barrier. Can I still mean something for him? At the same time I swap to a more pragmatic mode and think, "I did my best, if this does not work for him/her, I can not help".

I do have my own limits of involvement. I do not give my mobile number to the patient or his/her family. I give it to professional carers who may call upon me whenever they want. I also claim my days off and do not take my mobile with me and insist on good hand-over to the colleagues who are on call. I do try to get in contact with the GPs and on one side support them; on the other side let them do their work. I also talk about my problems with the team members, put them on the agenda of the MDM. I also take time to speak to the staff members about their problems. They usually respond well when they notice that I have similar problems. So sharing is an important thing. Finally I must confess, I forget easily things, and this is a mechanism which protects me from having prejudices and negative feelings. On the other side I must say I equally easy forget that

I borrowed somebody money... Which is friendly but not very practical. I also try to enjoy life, family and contact with beauty of the art, magnificence of old buildings and importance of the history. I travel far also to be for a while far from my patients and far from their problems. May be because of the benefit of distraction I love teaching and love students. I can be honest with them and I know they experience this as important.

In palliative care we believe that the patient should be autonomous and should take his own informed decisions and we are his or her informers. However, this noble gesture makes us completely vulnerable and unprotected in cases like Peter. Any time I treat a (former) drug addict with terminal illness I experience the same. We, or I, personally, cannot switch so easily from the soft, sharing, believing and informing attitude to the hard, directive and bossy attitude the (former) addicts need from me to survive and to get better. This awareness comes to me with time, when I am dealing with patients like Peter, but sometimes it is too late. The patient chooses somebody else as a prey.

Where and how to find a gold middle? For me the answer is in the sharing with the fellow members of the team. I shared these dilemmas with the head of our psychosocial team. We had a good and lengthy discussion and I think this discussion was the most important for my own learning process.

Here is a short summary of the talks we had. I realised that I do not know much about Peter and Angela at all. I do not know how he was before the illness. As a child? What kind of person he was? What kind of husband, father, manager? Which were his passions, hobby's and weaknesses. How was his relationship to Angela? I have heard the story mainly from Peter himself, not much from Angela and certainly not from Peters' children. Was Peter abusive to Angela? Did he ever had an experience of sexual assault with rectal penetration? (John! How on earth should I ask him about this?). The same about Angela? Who is she when she is not carrying for her husband?

Although in some discussions with them both I took the role of "the boss" to avoid Peter will not allow Angela to be open and to tell me anything, I did not dare to confront Peter with his behaviour. I just chickened. How is really his insight in what kind of mess he is making around him? Shouldn't I call help from psychologist here, or may be psychiatrist? May be not for Peter (I broached this with him once) but for us, for the team? To get our insight in how do we act in this difficult situation.

I became aware that we do our job because there is a desire of "rescue" people from pain and distress. It is very hard when we can not achieve this or the patient undermines our attempt to help. Sometimes we have to watch patients suffer and we are powerless to help as they won't let us help them.

Yes, I realise that in Peter's tenesmoid pain there is an important psychological component. Once Peter was busy with two other women in the Day Care to play cards. I went there to get him for our meeting. For a while I observed him through the window. He was joyful, laughing, clearly enjoying these rare moments. I even hesitated to get him out of there for a talk. When he saw me, his face changed and he declared that the new medicines I gave him did not help and he is now in excruciating pain. So may be we should leave all the medical stuff away from him and start to explore his psyche and coping? Could we teach Peter to apply special strategies to cope with his suffering?

The problems of the nurses are a reality. Can they push themselves to resume or do they dismiss the patient. Sometimes they resume physical care, but they dismiss the patient emotionally. Peter senses this very well, as everybody would sense this immediately. Can I talk about this with the nurses? Would they allow me to discuss this? Can I help them to try again, doing things better, even if I have my own doubts about my own behaviour? Should we rise these issue during our weekly MDT meeting, or should we do this on a separate occasion. How can I deal with so many nurses talking about such difficult thing?

Patients like Peter are "frightening". They challenge the rules and do not fit nicely in one box. They make competent staff feel very disliked, because nothing they do is right and they do not give us the reward of feeling we are doing our job well and this can lead to serious self-doubt and even "burn-out" if not dealt with. How do we recognise this problem, what are my responsibilities here? Nurses (and doctors) who distance themselves from Peter, make it hard for those who try as there is no support for their efforts of trying when they start to tire and feel self-doubt.

Peter probably experiences severe mental pain. He was a manager and he is an intelligent man. I did not ask him for hobbies and passions, except that he told me he loves to go Saturday to watch the football match. I need to think how he can be helped to use his mind and talents. What can absorb him other than what he has lost. Who in my team will be most competent to explore this? This sounds like finding

a fitting gift for very critical adolescent daughter. I was never good in this.

I have done everything I could to try to control his physical pain. He has not really complied with these efforts to help him. He would not let me help Angela as he fears a nursing home. This fear increases his control behaviour, but this may in turn lead to Angela's illness, her inability to cope and to psychological breakdown. Sadly I have seen this before, carers dying or divorcing their beloved. And, as an honest doctor, you can never say I have done everything! There may be, and certainly are, other people who know much more about this kind of pain. Should I give up looking in the medical corner or should I regularly try new therapies and new tricks?

For all this the team needs to be well organised, sensitive to this kind of problems. What if I shall read this elaborate during the MDT meeting? Do we need an access to somebody from outside the team, just to have a chat and support, just to know we are not insane and we are on the right track?

What did I learn out of this?

Obviously I was in this kind of situation many times before. After a while I was always stuck and could not go further. This is the first time I analysed whole situation in detail, spoke to other team members, got many, many suggestions. I feel that my dealing with Peter is still too medical and too physical. He refuses this kind of care. He needs a more spiritual support, somebody who will meet him at this level, will understand him, will understand them both. My medical training did not give me many tools to deal with these problems. Now I know I have several team members with different talents but the same passion, but also new aims in my learning.

References

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