

HEALTH Patient Journey Mapping - Post-Consussion Syndrome

Phase	The accident	Into the rabbit hole Going home, not knowing exactly what to do	GP appointment	Adapting Resting at home, trying to find a balance (rehab @ home)	1st line care Referral to 1st line	2nd line care Referral 2nd line (neurologist, ct-scan)	3rd line care Referral to 1st/3rd line for rehabilitation	Rehabilitation Going back to normal life as much as possible
Time span	1 day / split second	2-4 weeks	Waiting on the appointment: 1-2 weeks	Waiting on the appointment: 4-8 weeks	Waiting on the appointment: 8-12 weeks	Waiting on CT scan: 1-4 weeks	Waiting on result appointment: 1-7 days	Slowly getting better: depends per person
Actors			Appointment: 30 minutes every month as long as needed	Constant towards recovering	Appointment: 30-60 minutes every 1 or 2 weeks for as long as needed	Appointment 1: 40 minutes CT scan: 5-10 minutes Result appointment: 15 minutes	Appointment: 40 minutes every 6 weeks for as long as needed	
Touchpoints	<p>The patient gets hit against the head. The person will go through with the activity or will stop and rest for a short time.</p>	<p>The patient will have some pain and maybe rest a bit. But will return to their normal life as soon as possible and as good as they can. This starts to fail. The patient will experience difficulties with the environmental (not able to transport well, environment overstimulated, not able to go to the supermarket), economic (can not go to work), and social (not able to study, meet friends and do fun activities with housemates) level. However, the patient believes they will soon be better.</p> <p>Social support will be careful but over time, when the patient still can not come, not get why the patient is not there. There can be a lack of recognition.</p>	<p>The patient can not resume their normal life. They struggle and do not know how to get everything done as they normally do. They do not know what is happening, think it will be better soon, and search for help from the GP.</p> <p>Social support will mostly not get why the patient can not come to an event or get the work done. The patient promises they are there next time but is not. Social support can pressure the patient to do more than they can.</p> <p>The GP will do some tests to see if there is permanent damage. This is not the case so the GP says the patient has to rest and that it will be over soon.</p>	<p>The patient can not resume their normal life. They struggle and do not know how to get everything done as they normally do. They do not know what is happening and how to get better. They are alone a lot because they are overstimulated quickly.</p> <p>Social support will mostly not get why the patient can not come to an event or get the work done. The patient promises they are there next time but is not. Social support underestimates how sick the patient is and can pressure the patient to do more than they can.</p>	<p>The patient is taking the help they can get. The symptoms are not necessarily getting less as the patient is receiving care.</p> <p>The physiotherapist is guiding the patient through different exercises. They look at what the patient is able to do. Together with the patient they try to set up an exercise plan, for example for balance or strength.</p> <p>The occupational therapist or psychosomatic physiotherapist is going through different exercises with the patient. Figuring out where they can change their life to feel better.</p> <p>The psychologist is treating the trauma the patient may have experienced. They can also present the patient with cognitive behavioral therapy.</p> <p>The optometrist has a medical examination of the visual disturbance the patient is experiencing and determine the right approach and treatment.</p>	<p>The patient is relieved that there is no lasting damage visible on the scans. Out of frustration they investigate what it could be and they read similar experiences online. The patient finds recognition and has Post Concussion Syndrome.</p> <p>The neurologist makes a scan of the head and neck of the patient. They do not see anything unusual. The neurologist also looks at the symptoms the patient is experiencing and diagnoses them with a concussion, Post Concussion Syndrome. The choice is made if a reference to a rehabilitation doctor is needed.</p>	<p>The patient is slowly trying to rebuild their life through the programs they are presented with. They are actively challenging their symptoms to train their brain and to rebuild the boundaries of their ability.</p> <p>The occupational therapist or psychosomatic physiotherapist rearranges the patient's agenda to fit their abilities, to be able to rebuild their life.</p> <p>The rehabilitation doctor sets a program for the patient to rebuild their life and tackle some of the symptoms they are experiencing, like not being able to bear light. During that program the doctor keeps an eye on the process of the patient and gives guidance.</p>	<p>The patient is slowly able to do more activities from their normal life with help of the programs they received. They have found recognition through reading the experiences of others through (internet) communities.</p> <p>Social support has become more aware of the struggles of the patient. They are also able to have more contact with the patient.</p>
Emotions	<p>"Ah well, it's okay. I have a lot of pain but it will pass."</p>	<p>"When the children asked something, I could fly off the handle. Which scared me. Why am I reacting like this? They are just asking a question."</p>	<p>"I looked at the doctor questioningly. How? How can I rest with four children of which three live at home and two are very busy? I have a business and my household."</p>	<p>"There I was between the four walls. I've never been so lonely."</p> <p>"I could not anymore, I was empty."</p> <p>"My hardest moments I passed alone, while everyone thought I was okay."</p>	<p>"I had the idea that I could get started, that I could grow and tackle things."</p> <p>"I came home from physiotherapy worse than I left. And I kept getting worse.."</p>	<p>"I had all sorts of microbleeds in my brain that didn't show up on the scans. But these kept my brain from making connections in certain areas."</p>	<p>"Suddenly the puzzle pieces fell into place. I came to understand my symptoms"</p> <p>"Now, I know my body better. I know how to recognize the signals and act on them."</p>	<p>"We crossed the finish hand in hand, together as a family. In the future, we will certainly face life together with great pleasure, hope and strength.."</p>
Challenges	In the shock of what happened, but not realizing the seriousness. There is pain, but the pain will probably leave in a few days. The patient is trying to make the pain go away as soon as possible and not have it affect their day. The patient is underestimating the symptoms and hoping they will get better in just a few moments.	Trying to continue life as normal, but feeling worse and worse. More symptoms are showing up as the patient tries to continue work or studies until it feels completely impossible to keep up with everything.	At this point, the symptoms have taken over daily life. The patient acknowledges the symptoms and is trying to find help. The patient also has a lot of questions to which they are trying to find answers. The GP will most of the time not send them to helpful care because of a lack of knowledge. The patient will not feel recognized and helped.	The patient is feeling restless and is dependent on the people surrounding them. The patient is feeling useless because they are not able to help or accomplish normal or any tasks. The patient is resting a lot and cannot do a lot. Everything which entertains them makes them sick. So they typically stare at walls all day. The patient is not getting any care. They feel hopeless, confused, and alone.	The patient is hoping to get help. However, when not getting the right help they can feel misunderstood, unacknowledged and/or unrecognized. They will then also be confused about the cause of the symptoms. In this process they can feel very alone and defeated. The patient is initially very hopeful and then disappointed when the preferred outcome is not met.	The patient can feel tense in awaitance of the CT scan and the outcomes. However, PCS patients will receive the good news that there is no damage visible on the CT scan. When the neurologist addresses that they have a concussion and/or PCS and will inform them about the symptoms this can give the patient a feeling of recognition and understanding. However, too many times this is not communicated to the patient. The patient can feel misunderstood, unacknowledged and/or not recognized. They will then also be confused about the cause of the symptoms. In this process they can feel very alone and defeated.	The patient is still seeking help to be able to deal with their feelings. When the rehabilitation doctor addresses that they have a concussion and/or PCS, inform them about the symptoms, help them to cope with this and get better, they can give the patient a feeling of recognition and understanding. However, too many times this is not communicated to the patient. The patient can feel misunderstood, unacknowledged and/or not recognized. In this process they can feel very alone and defeated. There are also rehabilitation doctors who tell the patient 'you will not be able to go back to the old you'. The patient can feel helpless, depressed and in shock by this news. However, in a lot of cases the patients do get better after several years.	If the patient has not been told they have PCS up to this point, they will most of the time find help through the internet. Think of googling symptoms and finding PCS communities. This can help them find recognition and support. It will present them with information about their symptoms and their possibilities for treatment. These new found possibilities, already received care (1st line, 3rd line) and newly increasing energy will help them integrate more and more in their new life. This could result in them becoming completely healed, not experiencing obstacles in their average daily lives or becoming better for a good percentage, depending on the conditions.
Design opportunities	There can be more prevention by creating more recognition and acknowledgment from society. For instance, at paid rugby and football associations in the Netherlands, there is an easy-to-follow medical directive on what to do when you get a hit on your head. Stopping with what you do and taking the accident seriously. Sadly, we do not see this awareness often outside of paid sports. This is a good design opportunity to prevent symptoms from getting heavier.	In this phase, people or their social support will often start to search online why this is happening and what they can do. Online (e.g. on thuisarts.nl (made by GPs)), information about symptoms and what to do with a concussion after the first 2-3 days of the accident, is hard to find. Therefore, a good design opportunity to give people a grip and explanation on their concussion is more open information on the internet (e.g. on Thuisarts.nl).	A GP does not have a medical directive for a concussion that holds on longer than a couple of days. All medical directives of GPs can be found on nhg.org. However, there is nothing on there for the long term when searched on 'commotio'. The main design opportunity is to bring awareness to PCS at the NHG so they will do research and develop a medical directive that GPs can use to send a PCS patient to help care.	If the design opportunities in the previous three phases are implemented. This will result in a patient which feels recognized and helped. They will know better what to do. Still, if the patient is not making enough improvement or stagnates or even goes backward in their recovery, they need to go to the GP again for more help. The GP must know what to do by having a medical directive on the website of NHG.	In this phase there is the opportunity for expectation guidance and more communication on the effects the treatments have on the patient. This could be approached by the psychologist, as they can already be present in this phase. To be able to truly be of help for the patient, the different caregivers in this phase could collaborate. The GP could also hand out flyer with information on what to expect. Another design opportunity would be to look at the earlier referrals to 1st line care, stimulated by the medical directive.	As the patient gets more insight on what they are experiencing in this phase, there is a design opportunity in making sure that the information, explanation and recommendation is presented to the patient as clearly as possible.	A PCS patient in this phase is often very frustrated or disappointed by the experience they have had and the duration of their symptoms. Still, they can be presented with wrong information about the treatment of their symptoms or the meaning of their experience. A design opportunity in this phase can again be a medical directive for the caregivers for the treatment they can give the PCS patient. In this phase it is clear that the patient has PCS, as they have already visited the neurologist.	In this last phase, the patient life is hopefully and finally slowly going back to normal. As the patient journey has been a rollercoaster of emotions, the design opportunity would be to create a community the patient can join to be able to process their experiences and to receive recognition and reassurance when they are experiencing a (small) relapse. It could also be very valuable for the experience to include this design opportunity in an earlier phase.