

Original Paper

Explaining the Concept of the Mental Health System to Service Users and Families

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The idea of schizophrenia being a mental illness is going to be difficult to explain and is best done by analogy. Like every illness it is organic which means there is something wrong in the body and the brain is just another part of the body. It is a mental not a physical illness but is still cured physically. The mind can be ill like the body so that like every illness you are ill with it and can suffer with it. One meaning of being ill is not being well.

The concept of a mental illness is difficult to understand. An illness just means you are not well so there is something wrong with you. Other terms used are disorder and abnormality: a disorder means it is not functioning right while abnormality means there is something not normal going on. Yet it has a wide range of cures some of which are more psychological than medical. These are beginning to become much more important to understanding the notion of mental health.

They call it mental health, but the causes are in the body. So, there are treatments here based on the scientific study of the brain's chemistry. It is an illness because of a chemical imbalance and this needs explaining so that we know that it is not all in the mind. It is not all just mental as there is also something wrong with you physically. The problem is in your biochemistry. Yet with this fact of being mental it is important to understand that it is not all in the mind.

Mental health is sometimes contrasted to physical health services emphasizing the important difference between the two types. This is pointing out each is as important for the other as if these are two sides to the medical profession. Under the designation mental health, you are obviously in the system but there is much more to it than just being in hospital. So, to understand the wider idea of mental health this needs explaining too.

Service users will be encountering these terms for the first time and the experience of being mentally ill is linked to the new medical language This needs destigmatising and explaining. Running through the plethora of new terms and language is the difficult idea this is an illness, but the question is how can the

mind be ill like the body? The answer is that they can both notionally be treated in the same way and the new terminology can help us realise this.

First to get across the idea of mental health we need to counterpose the medical terminology to the stigma labelling as both carry some authority. You need to explain both the stigma and the medical side at the same time. The stigma labelling can be colloquial, but the medical terminology is technical both of which carry different sources of authority. Firstly, though we need to explain the technical language and what it means by calling it an illness. This brings a lot of other medical terms into play and schizophrenia is the first term you are likely to encounter.

Schizophrenia is the *diagnosis* and like any diagnosis it signifies an illness. Yet it is very misleading as though it is medical is also stigmatising and this confuses the medical and the stigma. Some of the other medical terminology is very difficult here like psychoses and paranoia as they also sound dangerous though again, they are diagnostic. To explain them we need a full account of the mental health system before they become clear.

Although these new terms need explaining at the outset after a while in the mental health system you tend to pick up on the jargon even if it is confusing or not understood at the beginning. Like any illness it has a cause and a cure and in medical terms these are symptoms and medication though if they cannot be cured, we will know they can be alleviated like having a cold where a cure is difficult to find. To explain the illness these facets of it are in need of further explanation.

Then we learn there are symptoms of the illness called delusions and hallucinations. These are unquestioned beliefs which create mistrust which once *defined* can be seen to be not stigmatising, even in spite of their general usage. These are technical terms but are best understood and explained in layman's language: Hallucinations are just hearing voices and seeing things While delusions involved believing things no one else believes and are now termed unusual beliefs.

Families are going to want to know exactly what the 'paranoid' thoughts are, and it is best to give some examples specific to the person as every one's experience will be different. What I was paranoid about was I thought the CIA were after me for having caused 9/11. The neighbours were spying on me and passing information back to them and at some point, I believed I was going to be caught. In addition and linked to this I was hearing voices criticising me for what I believed I had caused.

These symptoms had consequences which are what makes the paranoid thoughts so difficult but are not a part of the thinking and the mind. Thinking I was responsible for 9/11 was terrifying as I thought I was going to be tortured to death for it and believing I had killed all those people caused intense emotional pain. This alongside the voices that were criticising me for it. It can stop you functioning and make you suicidal so there is a need to be treated for it in hospital.

They are going to seem bizarre and confusing until it is explained they are just delusions and that in turn delusions are just a symptom of schizophrenia. Again, that is going to make them sound dangerous as does hearing voices but there will be some insight into being mental. Then we will realise they are

technical terms so the medical terminology will help explain things as that what the 'illness' consists in. This is the state of being mentally ill.

The suffering will be very visible and families coming into the mental health system will be further distressed to learn that these consequences can make you suicidal. Understanding the mental health system will mean the good news will be there is much that can be done to help. To realise this, they are going to need an explanation that deals with the whole of the mental health system and how it works. This will also need to explain that at one time people will have been in the asylum for many years and this is still true of being under the mental health system, but we have come a long way since then.

So, it is going to be asked what exactly is a mental *hospital*: it is an institution and like any hospital it is there to provide treatment and care, treatment in the form of medication. There are explanatory links here to medicine and medical profession as medicine. They are part of the national health service. Like any hospital it has doctors and nurses so If you are ill you need doctors and nurses are there to look after you. They can prescribe the right medication and soothe the feelings of being ill with it.

The doctors are not the men in white coats are doctors. These were worn at one time as the doctors are scientists and know about the research going into the medical treatments. These are 'drugs' developed for medical *research* and a drug is a medication also called an antipsychotic. The word psychoses needs explaining first as it does not mean psychopathic. These drugs will become familiar to everyone as 'meds' shortened from medication.

The word psychoses also means an unchallengeable belief but this can be a bit misleading as there is the possibility of insight. This involves looking at a belief as a delusion to see whether it is real. At this point we need to draw on the notion of a delusion as something for which there is no evidence to challenge its unreality. This approach is called cognitive behavioural therapy which is another terminological approach in need of getting across to people.

Using these approaches once they become effective opens the door to using and understanding other medical notions What starts out the thoughts causing the terrible symptoms are thoughts so we know people are suffering from and we can get the idea of mental illness as we can see changes in the symptoms. You can see people *getting better* and *cured* form the illness. They *recover* and *get back to normal*. *The treatment is effective and not resistant*.

The problem with explaining things is that mental is a dangerous term but mental refers to the mind at the same time. This is another very important juxtaposition and maybe be further combined with illness, health and hospital to explain things. Then people will be asking what each of these are. The short answer is mental health is the absence of illness and mental illness *the condition* of being ill. We need to elaborate the issue in more detail.

A mental *hospital* is a hospital but the word 'mental' also signifies notions of the nut house, looney bin, funny farm which obscures the word hospital. It is a hospital designed to treat the *condition* of being ill, mentally. Like any hospital health care is provided so the notion of hospital can be counterposed to the

word mental. This very similar to the way the word lunatic can be juxtaposed to the word asylum and it should be pointed out that term is no longer used. Also, a hospital is a facility not a place of confinement. The hospital is not like bedlam as you get your own room which allows you to reflect on your life with the illness good and bad. This is quiet and restful and is complemented by being able to relax in the spacious café or going walking in the surrounding woodland. You can go walking further afield and come back to the hospital when you feel ready, and a change is as good as a rest.

My mental hospital was in a town centre and didn't have high walls around to keep you in. You could come and go on leave, and you weren't restricted to staying on the ward. So nobody tried to escape. Indeed, many were grateful for the help they had. After a while you get used to being in there as you understand the place and the people. Then it is less stressful which can help with the illness. Here you will take advantage of the therapies available until you start to feel you can leave.

Mental also means insane, mad and crazy in order of the danger signified and putting the label mentally ill on someone is going to be as bad as calling them schizophrenic. Here again the stigma though both can be counterposed to the medical side of the term which makes it understandable. I found the label mental health much better, and it signifies the wider mental health system and then it needs explaining what the different parts are and what they do. This includes mental health day centres and sheltered housing in addition to hospital.

At this point another difficulty arises in using technical and medical versus the slang as there are examples in the media which confuse the two. In particular in the movie *The Terminator* the Character *Doctor Silverman* there is a scene where these are linked. He says about the character Reece "in technical terminology he is a loon." Here explaining technical aspects of the medical Jargon is going to be difficult and need quoting examples to the contrary. One example is in the movie *Romancing the Stone* where it is pointed out "people go to psychiatrists to talk about their problems."

Psychiatrist is another term used and in need of explanation as people will not know what it means. Again, you can look up this in the dictionary a *physician* who specialises in the research and treatment of mental health disorders. This will emphasise the biological nature of the illness though it partly uses the word psyche to refer to the mind. You will familiarise use of language here as the physician will become your psychiatric doctor or Pdoc and more harmless as a shrink, short for head shrinker :-). Using this route we get to the notion of psychiatric hospital, that psychiatrists are part of the medical profession as mental health professionals and that they are one branch of medicine.

Doctors are medically trained and will know a lot about which drugs to use most effectively though they are often in disagreement for each other. They build up expertise the more contact they have with patients and develop preferences for the most effective medication and the senior doctors will know more than the junior doctors. They can give you and expert opinion which again is very reassuring and enlightening. On the ward people will see their relatives responding to *treatment* which is evidence against the stigma. Here the idea of curing the symptoms begins to come into its own and the patient will look and feel

healthy again. You can see what hospitals are and how they work which again will emphasize the medical side.

People are being *admitted* not committed but if the police are involved this difference needs explaining to relative as when ready they are also discharged. This even if they have been admitted to hospital under section of the *mental* health act and when once there are put under constant observation and not allowed out. These are the worst side of services as being confined like this is very stressful and can worsen or perpetuate the illness further delaying discharge. Hopefully though they will get better.

Mental health care is also there to provide care for the consequences of the symptoms not just to treat the symptoms medically. This leads the role of mental health nursing which is another side of services that needs understanding. Schizophrenia is frightening and emotionally painful and these feelings can be *nursed* and alleviated with soothing conversation and anti-depressants. Some Valium is used occasionally at the worst points though talking it through with nurses can calm you down through distraction.

People are also going to want to know what has caused the illness. Prodromal is the technical term here describing the cause and needs to be understood as well. The medical model will say the illness is caused by a chemical imbalance, but some explanations will go beyond this and recognise it may be stress induced. People will know about this so far as they will be familiar with terms like being driven round the bend or round the twist and of course once it is stress induced things will be perpetuated by the consequences of the symptoms.

Now that this is increasingly being understood new therapies have been developed such as using compassion to soothe the stress. Again, this involves difficult words, but it involves another way of looking at the workings of the *mind*. It come under the umbrella of mental health and the notion of a clinic is used. It needs explaining the difference between psychological and psychiatric then we get the idea that mental health is as much about curing it by talking as well as medically.

You suffer with it in the same way physically rather like having a cold. Once in hospital you can be sensitive to the suffering of the other patients and family members will be exposed to this too Then they will also feel sympathy for the other patients and so be grateful to the doctors and nurses. You will start to feel much compassion which can be used by your relatives to help lighten the stress overload and help soothe things.

Calling it an illness gives birth to the notion of a mental hospital. Some conditions need to be in hospital, if this is the only way they can be treated or in the case of mental health if they are severe enough? Like any hospital it is there to look after you, so you get well again and provide treatment? This is caused the acute phase and you stay in hospital only when you are going through the worst of the symptoms. Still there are many misconceptions.

In there you are on *a hospital* ward and are not locked up. You will be looked after and not in the bin. This will make you realise you are in a hospital and have not been 'taken away.' You are not confined for life either. The hospital was also in the town centre, so I didn't feel socially isolated. Other medical/stigma opposed notions needed clarifying.

One important juxtaposition of language and medical terminology was that the lunatics just turned out to be patients. Later another term was used, and I was called a service user once discharged which replaces “mental patient.” This was much more innocuous and emphasized the voluntary engagement with the help professions.

Visiting a *hospital*, you can see other patients responding to treatment. Then it is not bedlam, full of raving lunatics or people violently acting out their paranoia. They were just normal people, and this should dispel some if not all of the labelling of everyone being insane. Families can see relatives responding to treatment which should reassure them too as any dangerous thoughts can be removed with medication.

In addition to the medical side distraction is another therapeutic technique used on a hospital ward which needs explaining to people new to the system. This allows you to keep busy by being active on the ward as you can vegetate when in hospital. It helps take your mind off things and cures the stress of being bored. This allows you to be motivated and reduces any low mood from being in there and promotes recovery and discharge. It can help with the feeling of being locked up.

Using these approaches the brain can focus on other things than the delusion and engages the mind to think of other things than staring at the television. It involves trying to do two things at once? Like listening to a Walkman when hearing voices you can try to focus on one rather than another. The question is can you do the same with thoughts? The problem is that you can try thinking about something else but you cannot get these thoughts out of your head like a voice that won't shut up. This approach can be very difficult.

Hospitals are not there so that you have got to prove your sanity but instead to let you out when the symptoms are under control. Doctors are not there to keep you certified but they are consultants you can confide in so you can ask to get help. You consult with them about your illness as somebody who knows what to do about it to find out what to do to. They are not the men in white coats again.

Unfortunately, as we have seen there is some truth to the notion of confinement as people can be detained under a section of the mental health act. They are not allowed out and this is against their will. This only happens if there is a very good reason such as if there is risk of harm to self and others. Yet your rights are taken very seriously, and you can appeal under the rules mental health act to have the section overturned. It can be very difficult to be let out once detained legally in this way.

So, it is part of the ethos of the caring professions that they want the best for us so that we can get well again not that we are being confined because we might be dangerous. Quite the reverse in that under care in the community they want us to get out of the hospital so we can lead a normal life as possible. There are other parts of the mental health system that are very effective in doing this including day centres and sheltered accommodation. This is out of the bin and into the community and works very well.

Also important under the mental health system is the distinction between primary and secondary care. Secondary care is to provide care outside of hospital so again it is not that you are going to be locked up. Technically speaking you are in remission, so you still need to be part of the *system* of care. It is not all

about staying in hospital and chemical imbalances as it may appear and there is a need to explain it all to anyone new to the system.

Once in secondary care instead of being locked up again should you relapse mental health professionals will do everything they can to keep you out of hospital. They will only keep you in for as long as you need to be and thankfully most admissions are short nowadays. After this there are facilities for getting back into the community and you do not get institutionalised anymore. We do not lobotomise patients anymore and it all down to meds.

Instead of patients being frightened of each other because they might turn violent, they chat together and make new friends. This social atmosphere hits you when you first arrive on a ward and is a very assuring when you get there. No one on the ward is wearing a strait jacket.

The next realisation that follows instead of padded cells you have your bedroom and there are no locks on the doors. Instead of being confined in a cell you are free to sit in the dayroom to have some company and walk around the grounds of the hospital to get the feel of the place. Like any hospital you are on a ward not locked up.

Sometimes in hospital is like going to a night class with interesting things to do and is an opportunity to meet new people. This chat again stops you being bored which is depressing and stressful to the point it could be serious. The chat can distract you from relapse and the voices, instead of withdrawn when hearing them. Importantly the staff both nursing and Occupational Therapist can do this if the patients are up to this. After that the ward had a nice friendly atmosphere and I was content just to watch the television.

So when you get to hospital you will notice not everyone is visibly suffering and are not isolated and withdrawn. You will put this down to the care provided and realise instead of being locked up disturbed people appear to be in a normal state of mental health. Once you have been on the ward for a while you can see people responding to treatment and being discharged which inspires some hope the doctors know what they are doing. Then realise the mental health system is what it says it is and there is no desire to escape.

‘Hospitals’ are often thought of as prisons. The impression of an asylum is that it will never let you out. Yet it is the goal of the mental health system to let you live independently not keep you locked up in hospital. The medication can help with this so far and once stabilised there is support to allow you to live outside the hospital. The transition to this we have noted takes place through secondary care and this involves the process of overcoming dependency and institutionalisation characteristic of the old asylum. Being on a ward can be boring and may feel like you are under a lot of pressure. All this can be stressful and can combine with the symptoms to make them worse. It is known that stress can cause psychoses so getting off the ward and going home become very important to alleviate this. This might first involve moving into *sheltered* accommodation which may feel confining in a different way, but we have come a long way since the old asylums.

Even in spite of the restrictiveness of being on the ward you can become dependent on living there as you learn to rely on the 24/7 help. You can begin to wonder which situation is worse the confines of not being at home or the isolation once you are let out? Then the question arises how will you cope without the different forms of support? One answer to this is to visit a day centre while still on the ward which also has staff to support you as well as having the possibility of making new friends to rely on once discharged.

There is a natural transition from being on a ward to going to a day centre and if you make new friends this allows for continuing the social contact outside of both. This might first require living in sheltered accommodation which is also 24/7 but that allows for more personal space than being on a ward. The homely feel reduces the stress of being on a ward and is better for the psychoses as is the feeling of independence. Once stabilised on medication there is less need to rely on other people which helps with being discharged.

Living in sheltered accommodation is communal like being on a ward. In both situations you have your own room, but it feels more like home than being in hospital. You can personalise your own room so it feels more like your own rather than the institutional style you would find in hospital. You can be on your own more happily when in your own environment and be alongside your friends rather than other patients. Staff are still there to support you but making friends can be better than this sometimes.

That support can encourage independence as you begin to get out and about with your new friends and live a more normal life. This is better than having a chat with the day centre staff and provides more opportunity for keeping distracted in life. In the end going out with the staff is less possible and is more fun with a friend. There is more emotional depth involved which in turn is more therapeutic. You can still talk about your problems but with friends this is more soothing.

Living in sheltered accommodation is a half-way house between hospital and living on your own. Like a hospital it has a full-time staff and provides care and support but in a community setting. There is more freedom than in a hospital and it doesn't feel as confined. It provides safety from the stigma without having to provide a context which completely escapes the society. Once discharge there is much more going on than in a hospital to get you interested in life again which will help prevent a relapse and going back in.

Ultimately though the goal is independent living is to have the semblance of a therapeutic and active normal life. The system can help with this, but it takes a communal living to help get to this point. Once again you will have formed relationships that can keep you active and interested in life, without dwelling on your symptoms all the time. Friendships are deeper relationships than you have with care workers and are more therapeutic though in some cases people end up very isolated.

At all these points day centres become very important as the process of deinstitutionalisation both from hospital and sheltered accommodation is very stressful. This on top of the other symptoms that could trigger a relapse. Day centres offer courses that can help take your mind off things and provide a therapeutic distraction. They can also focus on relaxation techniques for calming the symptoms down. It

provides yet another venue for meeting new friends and offers courses as things of the same interest to talk about.

Once you absorb all the terminology you become compliant with the mental health system. Instead of wanting to escape its confines you are a lot happier to stay there. It does take some adaption to get used to living in the institutional setting, but you soon get adjust to it. The you put up with the restrictions because you know it will make you feel better. Although confining it was never a prison and I found the feeling of being locked up depends how long you are in for.

Moving out of sheltered accommodation is sometimes a trade-off between greater self determination and social isolation. You will be losing staff support and frequent contact with your friends. At these points day centres become a bit of a lifeline though meeting friends and partners there can be difficult, and attendance is limited to a couple of days a week.

Meeting partners in the mental health system can be hard as you are thrown together from all ages groups and walks of life though the other side to this is that it is a bit like going to university. The social contact at day centres may not be enough and it might be necessary to make contact outside of the mental health system. The system is sometimes not effective enough in providing the support and care it is aimed at providing.

Moving out of a mental health project means less protection from the stigma and these fears will be combined with any worsening with the paranoia. It is not clear that being outside the system is always going to work and it may be that independence is not always as good a thing as it may appear. There are problems and potential solutions that need to be taken into account here. This is again this is another learning curve.

There are serious implications here for the consequences of your symptoms. Lack of emotional contact is stressful and there is nothing to distract you in life with the illness. You cannot do a lot of things like eating out or travel when you are on your own and will not be leading a normal life. Life will then be boring under these conditions and the stress of this could have you back in hospital. Once having got used to the life outside is the last thing you want as it is more stressful.

Often too family contact will be limited but in case of social isolation these links become crucial. I feel more motivated when I see my family and am able to go to exercise with my mother three times a week. I can live it up after this and go shopping or eating out. I feel a lot fitter and much more cheered up. In contrast sitting around the house on your own which can make you feel depressed. This may otherwise mean you are unable to make the effort to be more active. It is family that has made the difference here. Yet family contact is only part of the story and after it there are problems for thinking how to fill the time in. Being bored for long periods can make you depressed and it is imperative you find something else to do when you are left on your own. Often it is best to schedule something else to continue the good feelings once seeing your family has ended. Again, it can be difficult to get an interest in something when depressed with schizophrenia beforehand.

The answer in my case was to join a local archery club and after being calmed down and cheered up by my family my mother would drop me off at the club where I enjoyed doing something else, I was really interested in. I told them about my schizophrenia, and I was surprised to find they knew what it was. Gong to archery was possible three times a week and filled much time in and gave me something to look forward to in between sessions when inside the house.

This came in useful for as the mental health system wasn't able to offer anything I so enjoyed like this. I started doing some courses at the day centre and focused mainly on the information technology but over the years I had done so much of this I got completely sick. There wasn't much else that took my attention so I could have ended up being bored with that place too. It may have been necessary to try and give something new a try, but I wasn't sufficiently motivated to do this.

The system has an answer to this so far and it is possible to get mental health support from an adviser at your local further education college. It maybe possible to have a mental health assistant to sit in class with you so you are not on your own. They can help with the social side and if they can support you emotionally it means not becoming depressed so that doesn't make you drop off the course or lose interest in what you are studying.

Again, this is a kind of halfway house in between the mental health system and the real world as the skills and challenges it involved can be used to participate in the workplace. Taking that step of finding a job is another way to be supported with life outside the system and the employment service can link in with employers who are knowledgeable and sympathetic to schizophrenia. Again, this gives a feeling of increased self-determination and compared to being notionally locked up in hospital and is a very different outcome.

Yet there are problems which the system can only help with so far as sitting in a class outside the mental health system is a big step and requires no small amount of confidence and courage. Having a classroom support here can reassure you but much strength has also to come from you. The situation might be stressful until you get used to it and the first lesson will be the worst. In time you get the feel of the place and afterwards you might really start to enjoy it providing the stress doesn't trigger a relapse.

The difficulty I encountered with sitting in on course was that people were discerning the paranoid thoughts and there was no way of disguising them, particularly if I was getting paranoid about the other people in the class. My immediate reaction was to run but the support stayed with me until eventually the thoughts went again, and I felt they might not have been noticed. It was easy to be more distracted in the class as I had a natural ability to enjoy and understand education.

Other more difficult problems with getting outside the system is that with hearing voices and having paranoid delusions mean being able to concentrate will stop the ability to participate in things, whether that is concentrating on what the teacher is saying or focusing on an archery target. Often though people having frightening thoughts and critical voices are so terrifying or painful that they become isolated and withdrawn. Instead of enjoying a course they can end up suicidal and are constantly in and out of hospital.

Conclusion

Living in the mental health system is a learning curve which begins with the confusing and difficult understanding of what a mental health problem is and this requires distinguishing between the public image of the stigma and the medical side of the coin. After that we begin to know the ropes of the system as we move through the different parts and how they work. The goal of all this is to promote independent living though there are problems with doing this. All this is a learning curve for service users and families and will take some explaining on the journey we go through from initial diagnosis. Good advice from mental health professionals can help with this.