The impact of parental mental health on children

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I hope we can all agree that mental illness is a funny business. First of all, we define it as an illness, and I hope to convince you later that, from a child's point of view, there is still some benefit in doing that. However, yet, what we, the observers, actually see, hear or feel is that somebody we know has become more extreme in the things he or she says or does, or that they have actually gone what we might define as "beyond the pale".

Even within the mental health services, there remains a big muddle, in my view, about how we think about these illnesses. If you go into a mental health team, you will find some people be using socio-cultural, some traumatic, some people relationship theories and others conspiracy theories; all kinds of different theories, which often vie for dominance over the kind of authorised medical explanations. Therefore, it is not very surprising that few patients, and even fewer relatives, actually receive any coherent explanation of their illness, the causes and its nature.

There are people who say that this is not a bad thing because this relative avoidance of defining the illness allows people to form their own opinion. Patients, as well as those close to them, can work out their own ideas, and that that might be respecting their human rights.

However, for one group of people - the children I will be talking about - the business of failing to explain can itself really be seen as an infringement of their human rights, and particularly under Article 12 of the UN Charter on the Rights of the Child, because children and young people receive less, if any, explanations than those of the people I have already mentioned. This, in turn, denies them the opportunity to understand what is happening to them in a family in which mental illness may have become the dominant atmosphere or set of relationships.

Thus, this lecture is about about how to correct what I believe to be an injustice, and the consequences of either doing or not doing so.

I thought we might quickly canter through some of the figures about the issue, and then we can move on to the more interesting question of what the young people and children actually think and say themselves. In England and Wales, Aldridge and Becker estimate that there are about 65,000 children designated as young carers. I have to say that "young carers" is a tricky concept because it used to attract money, in the sense that, if you were called a young carer, the local authority could get some money to give you a support group. However, most of these children do not think of themselves as young carers. They usually think of themselves as surviving. We are talking about children of any age – five upwards. If you are a young carer of a parent with a physical illness, you may have a restricted life, you may lose some fun, you may have a lot of limits on what you can do, but you would usually expect to get some recognition for what you do. The problem about being a child of a parent with a mental illness is that the caring is much more likely to be an emotional business. You might also be giving out medication to the parent. You might also be picking up the pieces when a parent has self-harmed or attempted suicide and calling in the emergency services. It is also quite possible that you will not receive any recognition. It is quite possible that it will not be acknowledged that you are doing anything valuable. You might even be blamed, or said that you are causing the distress. It is a tricky idea and I will come onto this a bit later.

However, Aldridge and Becker also reckon there are about a million children and young people in the UK (not just England and Wales) who are significantly affected by a parent's mental illness. If you look at patients in the sort of general run of mental health services, you will often hear it said that not many of our patients are parents. This is absolutely untrue. About 68% of female mental hospital patients and 57% of males are parents.

About 70% of children of a parent with mental illness do report significant difficulties in their own emotional lives, in their managing to concentrate in school, and a whole range of other things, which I will not focus on today. However, I will focus on the things the children specifically complain about. If you have one ill parent, you have got about a 70% chance of having minor adjustment difficulties at least. If you have two parents with a major mental illness, you have a 40% chance of actually developing a serious mental illness which sounds terrible. It is not actually quite as bad as it sounds, because, first of all, statistically, you are still less likely to develop it than to develop it and there is quite a lot that you could do if you knew about it, or that somebody else could do if they knew about it and did something about it, that could help protect you.

So, I thought, before we go any further, it might be just interesting to hear just a few young and older children talking. The youngest, Ricci, is about five here, and later, you will hear his brother, who is a bit younger, although he is also five because it was filmed a bit later. I will tell you the context these films were made in shortly but let us hear a bit of what Ricci said about him and his mother. [Recording plays]

Having a fear of catching the illness is not uncommon. This one, with Matthew, is a little more light-hearted, or at least it starts that way. [Recording plays]

Now we have the first of two sisters, Chineye, who was 14 when this was filmed. You will see her quite a bit tonight. [Recording plays]

As you can see, Chineye has a sister, and when we talk about resilience and protection, having two siblings sharing the experience is a very important potential part of protection. However, Diane was an only child. [Recording plays]

Diane describes a violent situation that is abusive, and not all parents are violent or abusive. In fact, many parents with a mental illness will try terribly hard to protect their children if they are aware of the impact they are beginning to have. In the project we are running, that has been a very important thing: as the parents and the children become more aware, so they become more supportive. This is important. This is Ricci's younger brother speaking a little later on. [Recording plays]

We have come across something, which, in a way, is obvious, but of which we did not think of initially. When the parent has a mental illness, children who do not have well-formed language are actually much more vulnerable, because, in our culture, people often think that a child who does not speak clearly cannot hear, which is a strange concept. The children who can experience the confusion of a parent with a mental illness but cannot articulate what is happening to them, and cannot probably even articulate what they are experiencing with the parent, find it much more difficult, even later, to retrospectively make sense of what happened to them.

Now, little things have a big effect. This is Chineye, helping us with a group of children, four years later. She talks about such a small thing but it is the kind of thing one might not think about. [Recording plays]

It is a poignant scene. What do children and young people say that they think they need?

The thing they want most, always, is for somebody to tell them what is happening. They want somebody to be straightforward and have a frank discussion to help them think more objectively. Another key wish is to have somebody they can talk to who is not a counsellor. Indeed, they explicitly do not want a counsellor because they do not want to think of themselves going down the same road. They are very relieved when they meet other young people in a similar boat so that they know they are not the only ones. There are young carers' groups, where young people who have had similar experiences can mix, share experiences and have some fun. They would love to be able to understand mental health problems properly; to know that they are not responsible because, quite often, they may have been told they are; to deal with their fear that they might catch the illness; and they would love to know how mental health services work, but many people in the country would like to know that.

They want to know what to look for if their parent is becoming ill, but, as you will see, I shall put up a slide about my experience in Merseyside about 10 years ago. They often know exactly what to look for although this is often not recognised by the professional services. They want to know that what they see and their knowledge of when the parent is about to relapse or have a breakdown is correct. Unfortunately, sometimes they know things that the professionals do not know and have never thought of. They would like to know of normal behaviour patterns for adults - very tricky! They would like to know how to access help and to have their contributions be recognised as well as having their knowledge of their parent to be listened to and respected.

I went to a big presentation up in Merseyside, in 1999, and there was a group of young carers presenting to a big Department of Health conference on the family and mental illness, and all these young people were talking. Most of them were over 16, but they had been looking after a parent for many more years than that. They were very angry, and they said that the worst thing of all was when the mental health services got involved, because, if it was a crisis, a compulsory admission, they would kind of come in SAS-style, cart off the parent, and nobody would say anything to the children. Worse still they said that nobody asked their opinion or their advice.

So, this little lecture is about how we can change that experience for children and young people. They want an explanation and a chance to understand the illness. It really is the top of the list for all the children we have talked to. Obviously, that explanation needs to take account of what the children and young people may, uniquely, know.

I always start this lecture by being as depressing as possible because some of the stuff the kids say is very depressing, but there are things you can do about it. I am not asking that all children of parents with mental illness should be adopted; however, there was an interesting study, the Finnish adoption study, of all the live births of mothers with schizophrenia in one year. They were followed up, long-term, until they became adults. They were interested in looking at whether these young people developed schizophrenia. There is a theory that there is a genetic loading if you have schizophrenia, and on the genetic theory, you would predict that those children who stayed with their mothers and those children who were adopted at about nine to 18 months would have about the same incidence, and they did. Fortunately, these researchers did something which some researchers fail to do: they looked in detail both at the mothers of these children and at the adoptive parents. They found that, when the adoptive parents had managed to establish good, warm, fairly clear, firm relationships with their children, that the children's incidence of schizophrenia was no higher than the general population. So there is one protective factor: if you can have good relationships, it protects you. It is not a very new idea, but there it is. There have been many studies which have shown that, if children simply have a neutral, friendly adult, with whom they can discuss what has happened to try and get it into some kind of objective picture of what has been going on at home, then that itself is a protection.

Furthermore, understanding the illness on the basis of a good explanation is also one of the strongest protections. In fact, there is a study which shows that, if you compare the mental health of children, using a child mental health rating scale, there is a very significant difference between those who have had an explanation of the parent's illness and those that have not had an explanation.

Now, many young people know quite a lot. [Recording plays]

The point about that is that Ricci can actually discriminate. This ability is very sophisticated – he can discriminate between grumpy and irritable parents that are the way they are, and the kind of anger that is associated with his mother beginning to breakdown. [Recording plays]

Actually, Sabrina has always, I can tell you, always been right. Several times, she has called the crisis team and they have said, "Oh, you know, your mother is fine," and she has said, "No, she's not," and she has always been right. [Recording plays]

If you are going to explain – this is the key focus of this lecture – you need to engage the child's competence. You need to provide a medium which can connect the child, the parents and the professionals. It is no use giving an explanation which the parents will attack – that is the problem. It needs to be one that the other professionals, if they ever get to talking about it, which they often will not, do not criticise and it needs to be not patronising.

What do you think might be the negative effects on a child of having a parent with a mental illness?
Audience member: A very much reduced development in terms of their education level with their peers. I would expect sort of all sorts of things to be at a lower level. Yes, it can be.

Audience member: I was going to say confusion, a sense that the mat or the foundation under you is suddenly taken away.

Confusion or the sense the foundation is taken away is definitely a possible consequence. However, it can be that the foundation is turned upside down because the child becomes the foundation and that is a mixed thing. Some children will actually say, "Well, you know, I learnt things I would never have learnt, being in charge," but of course, they do lose a lot – not always their education. Chineye and Sabrina both got straight As and got into university without any trouble, but had a lot of emotional difficulties and difficulties, particularly one of them, with relationships, and also, you know, at one point, was quite suicidal herself. It can affect education because a lot of children will miss a lot of their education, or they will be very preoccupied during school time, but this is not necessarily true.

Audience member: Could it affect engagement with the normal social milieu?

This is very much true. Stigma and social isolation is very high on the list, and it is not only socialisation. It is not that the other children will bully them and say 'your Mum's a nutter' or "I don't want to have anything to do with you". As some of the kids will also say, they feel, because they have such different experiences, which they do not think they can ever communicate, it makes them pull away as well.

Audience member: The lack of engagement from the parent in those crucial developmental years, I would have thought that was fundamental in the development of self-esteem, and all those skills.

That is absolutely true. Of course, children miss out on fun, playing, feeling like part of a child group, plus this particular fear that they are going to catch it, and the fear that they caused it, which has often been rubbed in.

I am going to leave this business of why children do not receive explanations – we can discuss that later – but I certainly think that the best place that children could get explanations is in the growing number of young carers' groups. There are only about three or four hundred now in the UK, catering for maybe 30 or 40 children each, and if you compare this with the 65,000 figure it is not very many. That is a place where children often feel safer and would be willing to discuss it, in groups of other young people where they have fun – they go to the cinema, they go off and do walks and skating and different things. Also, at the kids' time workshops that are our groups which includes pizzas as well, we have found that kids are happy to talk about it and begin to get an explanation.

Now, I will now show you an explanation. It is a 15 minute film. We are going to watch it on DVD, which is slightly better quality, and this is a little film I was asked to do by the Royal College which children can logon to on the internet, or they can download it. You will see, it is a funny explanation. It was an extremely frightening film to make because we had one evening, and we had a group of children, all of whom I knew, whom we had to give different names for their protection, and I kept getting muddled abut the names. We had one little bit of money, we had a two-camera crew, it was unscripted, and I knew that if I made a mistake, which I did, it would be a waste of time. Fortunately, you will see that Chineye, who is the presenter – you have met her already – and one of the other kids, plus an animator, helped me rescue it.

It is deliberately technical, and the reason for that, even though it does not really give a mechanistic explanation of mental illness – you will see it does not – it sounds as though it does. The reason for using that is to try and help the children not get over-identified with the parent's feelings but to distance themselves. It is not related to diagnosis, so we tried to choose an explanation – although it is more relevant to some diagnoses than others – that gave them a more general idea of the way things worked. [Recording plays]

Audience member: I found that really warming, and I asked myself if a lot of adults would not profit by seeing it as well, because I think it succeeds in getting across a difficulty which obviously a lot of professionals, of which I am not one, seem to encounter within themselves in making this transition, if you like, from being an authority figure to being an aid in some sense. Of course, it is interesting that you had to evolve the explanation in order to make it stick, and that takes time and quiet circumstances in which to do it obviously.

Audience member: My congratulations at the outset because of the job you did in the time, but the thing which strikes me and I wanted to ask you is: what becomes of such an explanation when they bring that back to their everyday reality and the experiential life they're leading might seem on a different scale of measurement from the explanation?

The thing about that kind of explanation is that it is a useful discussion topic. We have given that to families and I agree with you. The reason I designed it for children is that I thought children could understand it. Most of the stuff that is given to adults is even more pathetic than explanations that kids receive. Kids can understand how things work. For adults, it is more difficult sometimes because we are not used to learning about how things work, because some of us are out of habit of doing that. So, I think it is absolutely useful for adults, but I wanted to design it for children because they could access it directly, and hopefully they would talk to the adults about it. Inevitably, I will find some professionals who will say, "Oh, well, this is not absolutely right, you have got it wrong." That does not matter, and generally speaking, I have found that, in terms of the feedback I have had, most parents who have seen it find it quite acceptable, even those who say "I'm not ill," because they are quite psychotic. It is a useful discussion topic that can go on between people because it gets over some of the problems of definition.

Audience member: I think I was really asking as well, if I may - when the child is witnessing perhaps violence or some sort of florid psychotic symptoms, do you get the impression that they can bring this explanation to bear in a way which will maintain their observing self, if you like?

It is no excuse for violence which is not that common, although there are certainly a proportion of families where there is a mental illness where that does happen. Certainly, inasmuch as you can create a reflective process between the parents and children, then I think it is possible to think about it, but obviously, in the heat of the moment, it cannot be.

Audience member: I gain the impression – I may be wrong – that most of the children you were portraying there had single mentally ill parents. I just wondered what the impact is if there is a spouse in the picture, because, obviously, they are quite often going to be acting as the buffer zone. I can see why the child might not find out many details because probably the other parents wants to protect them from what is going on, so is there benefit then for the other parent going to these kind of sessions to support them…?

Absolutely, and where there are, we very much encourage them. About 80-90% of the parents who come to our group are lone parents, although there is one or two who come as couples at the moment. If there is a well parent, and particularly if they can be helped to not be too involved in the illness and to be seen as a reliable other to the child, they can be very helpful. If, on the other hand, they try and “protect” the child, by preventing them from coming to terms with what actually is happening to them, then it is unhelpful. It is very important to try and engage them in realising that having an explanation is crucial. A lot of people, unfortunately, think that young children, for some reason, are either blind or deaf, and that, somehow, if you do not talk about it, they will not notice. It is very obvious from those young children that that is not the case.