

Introduction

Hello everybody you may all know me but for those who don't my name is Joann Tate.

I have been involved working as a Patient Carer for about 8 years. I was introduced to this work by accident. I thought it was some Community Health training, my friend, who dragged me along, was heavily involved with at the time. I was out of work at the time. Due to my disabilities I was unable to find work that suited my needs. Basically I was unemployable. I haven't looked back since.

It all started with Jools Symons and Chris Essen. I attended their Patient Learning Journey and boy what a journey I am on.

As you can see from the list of involvement I am not unemployable. I just changed direction. I have never looked back since. It wasn't an easy road but it has been very worthwhile, interesting and challenging. It was a massive learning curve for me, nothing like I had ever attempted.

(show list of involvement)

Overview.

I am going to talk about some research I was involved in as a Patient/Carer telling my story from personal experience how Patient Safety incident effected my life.

This research was a Random Controlled trial of Patient/Carer led Intervention. A 2-year pilot trial talking to then FY1's. The research was based in the Yorkshire and Humberside region. Harrogate, Bradford, Goole, Scarborough, York and Grimsby. Over 2 years. It is formed up of Patient Safety Champions' from all over the country. This is a Patient/Carer led teaching module to increase the awareness of Patient Safety within the medical professions. It was to try to develop a new teaching method into the existing curriculum

What Happened.

The FY1's have to have ongoing training and this teaching session was one of those training session they had to attend. All FY1's must attend.

The session of the day was split into two groups by random selection. Approx 10/12 in each class With prior approval, ethics and consent given. As our session was tapped for research purposes only The class was split into 2 one attending the traditional lecture and the other going to the Patient/Carer led group.

Questionnaires where given to the doctors before and after the sessions This was to show the whether emotions also occur before the session showing anxiety in facing patients who have suffered harm. This was known as PANAS. Positive and Negative Affect Schedule.

The 2 classes ran simultaneously. P/C told their stories. After the first story FY1's were then encouraged to ask questions. This was repeated by another story after the break.

The traditional class. A facilitator spoken to the class given fact and figures about Incidents, fraud malpractice. within the NHS. They also covered Health and Safety within the NHS such as different non slip flooring, direction marking on the floors, safe closing doors and other safety features the hospital.

I did observe both kinds of teaching. In my opinion the traditional class did not cover what I call Patient Safety.

The comparison was so different. In the traditional teaching session actual Patient Safety was only covered by figures and records of incidents and how it was dealt with if ever it was. All the information they gave in the class could be found on the internet.

A vast contrast.

Why use Patients/Carers

P/C use real stories and incidents that they had experienced. The consequences of Mis-diagnoses. Mis-prescribing, Procedures/operations that had gone wrong. The medical professions' not listening to patients/carers (Dr's knows best) sort of attitudes.

The traditional lesson I observed was just another lecture. Dr's attending this did not seem very interested or interactive. It was a matter of the Dr's had to attend as part of their ongoing training, this showed by their lack of interactions and involvement.

How did it Effect the students.

The P/C sessions was varied. I spoke as a patient in several session. One session was very defensive stating the work load, fear of reprisal, filling in forms that took up precious time. speaking up for fear of putting the carer in jeopardy, by ringing their seniors or speaking up.

This class I might add was a large class the first we did and I don't think they really wanted to be there.

In comparison another was very quite not hardly any interactions and questions. I don't know the reason for this they could have been because they were bored, not interested or shocked

Then we had some that were very emotional for the Dr's the P/C stories effected them greatly and on one occasion a Dr had to leave the room.

Over the session a lot of questions were asked and the Dr's during the breaks did come and talk to P/C on a personnel level saying they found the session very eye opening and interesting.

I don't know the outcome of the research I was there to tell my story.

Me: What I got from the experience.

Before the sessions started we had meetings and briefings regarding the research. We got support and encouragement, throughout the trial. It was a team effort, it was never them and us. The Research Team: Vikram, Jools, Naomi, Zoe and Anna. They talked openly in front of us. We were valued for ourselves and our work.

Crucially we were given debriefing after each session so we could openly express our emotions. The FY1s also offered the opportunity to speak with the research team privately.

We formed a tight knit group. All the group had different experiences of incidents from death to 'life long disabilities'.

I personally learned a lot about myself during this research. I always had 2 stories or so I thought. I was going to tell one of my stories and it was pointed out that both stories were connected. I had been carrying two different stories for years. When in fact the 2nd story was just the outcome of the first.

It was a revelation, everything slotted into place regarding my knowledge on going ill.

KEY MESSAGE

The key message I hope we got across to these young Doctors is

"IF IN DOUBT, DON'T"

Ask questions if you don't know or understand.

All I ever wanted was an apology and explanation why my operation went wrong. I got neither. I wanted somebody to say to me "We have made a mistake" and give me the relevant treatment at the time.

All I got was a cover up, notes going missing, being passed from one doctor to another, not given the right treatment, being ignored and not listened to. This then led on to my existing disability years later of Fibromyalgia, chronic depression which I now think could have been avoided.

So why be involved at the University.

I am involved because.

1. I enjoy the work
2. I get fulfilment
3. I get satisfaction from the work I do
4. I am learning and teaching tomorrow's doctors.

It's given me a new lease of life and confidence. I have found talents I never knew existed. I am able to pass on my knowledge and experience in the hope that we can

have better doctors in the future so nobody else has to battle with the medical profession as I have done over the years.

Our future doctors will listen and learn to work with Patients/Carers because they have a wealth of knowledge and experience.

I learnt during my time working at the university to come to terms with my illness through better understanding of my condition and how the system and how to use it to help me get what I need and want so I don't waste the doctors time or mine

I am not the angry patient I was when I first walked through the University Campus. I am proud of what I do and what I can give. I have learnt so much.