

Carol Beech

The lived experience of the impact of receiving a dual diagnosis of Rheumatoid Arthritis and Parkinson's.

Title and Abstract

The aim of this study is to explore the impact of a dual diagnosis of Rheumatoid Arthritis and Parkinson's and the lived experience of this. The participant is both a friend and colleague R who had a successful academic career and a very active healthy physical life until this diagnosis. Using an unstructured interview style I follow the lead of my participant whilst identifying specific themes of his lived experience to explore. Some of these themes are practical others have a more existential emphasis.

I was impacted by my participant's reaction when he said that he hadn't had the opportunity to talk about his experience in this way and how it brought back the emotions experienced at the time. He talks about the initial impact of hearing the news, the fear and panic of the existential experience of loneliness at that point; the depressive thoughts and fears of dependence in contrast to the autonomy of his previous life experience; the image of self that is challenged and has to be renegotiated as well as relationships with family members, colleagues and friends.

My participant has lived in an academic environment that places an emphasis on the brain and can often neglect the body:

"it looks on the body as a form of transport for the head" Sir Ken Robinson 2007 ⁽¹⁾

this diagnosis changed that emphasis and placed fundamental importance on the body and its limitations.

Introduction and Literature Review.

Linda Findlay(2003) writes in her ' phenomenological study of living with a recently diagnosed multiple sclerosis'⁽²⁾, that there is considerable literature on the lived experience of disability, she quotes Charmaz 2000⁽³⁾ and Kleinman 1988⁽⁵⁾:

'the underlying existential assumptions that people hold about themselves and the world are thrown into disarray ' (Crossley,2000 p539) ⁽⁴⁾and Charmaz (2000) writes about the loss of self and self esteem.

Findlay refers to other phenomenological studies in this field and how they describe something of *'the body's 'betrayal' and 'a journey which is essentially lonely, confusing and challenging 'which is particularly relevant in this study.*

She describes the intertwining of body, self and world, the combination of sense of identity, present and future plans as well as life activities and relationships. She quotes Reissman (2003)⁽⁶⁾ as this work highlights how identities are formed and socially structured and includes in her final discussion the extent to which her participant's personal story may be a shared social story; whilst recognising that every person with a chronic disability has a distinctively different story to tell.

There are many chronic disabilities that people experience that will have similar themes; this study focuses on the dual diagnosis of two disabling conditions Rheumatoid Arthritis and Parkinson's:

'Every hour someone in the UK is told they have Parkinson's', about 120,000 people in the UK have the condition' Parkinson's UK⁽⁷⁾

Parkinson's' UK asks to hear from people to tell their story so that real life stories are on line for others to access; stories where people talk about a range of topics such as fear for the future, effects on children and concerns about how other people see them.

Parkinson's research mainly explores how and why certain nerve cells in the brain die and it looks for a cure such as stem cell research and gene therapy. Other studies examine gut bacteria and dopamine medication and the risk of developing impulsive and compulsive behaviours. Other research focuses on improving the quality of life for people with Parkinson's and looks for ways to improve sleep, depression, dementia as well as movement and turning.

Other relevant research into Parkinson's argues that the illness accelerates and intensifies changes that are normally expected in later life..Mendelson, Dakof, Skaff (1995)⁽⁸⁾. Brown, MacCarthy, Gotham and Marsden (1988)⁽⁹⁾ describe depression and disability as complex but highlight that the relative change and rate of change in disability is a factor in depression.

Other research into depression as a feature in Parkinson's, Gotham, Brown, Marsden (1986)⁽¹⁰⁾ found that depression did not significantly differ from the findings of elderly arthritis patients; both groups had depression characterised by pessimism and hopelessness, decreased motivation and drive and increased concern with health, in contrast the affective feelings of guilt, self blame and worthlessness were absent in both groups. However, there were individual differences in coping style and availability of support.

Some studies looked at healthcare professionals, Townsend, Wyke, Hunt (2006) recommended that healthcare professionals need to recognise the tensions that people experience as they negotiate symptoms, valued social roles, positive identities and daily life:

"addressing these issues may improve opportunities to support patients in particular contexts and enhance self management".

Charlton and Barrow (2002)⁽¹¹⁾ looked at a small study of people experiencing Parkinson's and found individual differences between members and non members of the Parkinson's society. For non members coping centred on maintaining as normal a life as possible and denying the condition whereas group members accepted the disease and its consequences and incorporated them into their daily lives.

Phenomenological research aims to go further it is both qualitative and relational it aims to provide a rich texture description of lived experience, Linda Findlay in her paper 'introducing phenomenological research' quotes Dahlberg et al 2008⁽¹²⁾:

'the overall aim of life world research is to describe and elucidate the lived world in a way that expands our understanding of human being and human experience'

The framework is a therapeutic interview that takes account of the relationship between the interviewer and the interviewee. It acknowledges how we interpret others through our own life experience yet we need also to be aware that our own emotions and experience this should not intrude or distort how we see, hear and understand the other's lived experience. It requires us to suspend our assumptions and be open to the experience, openness to listen; respect and humility as well as sensitivity and flexibility are essential. We need to be focussed on the other and their experience.

This study aims to explore a friend and colleagues story of receiving his dual diagnosis of Rheumatoid Arthritis and Parkinson's and the lived experience of this. Despite regular contact, through sharing an office and numerous conversations I don't feel that I had any real understanding of his experience until this interview. Most of our previous conversations were not 'real listening' experiences and often didn't allow time to fully explore feelings and beliefs; this interview gave permission to the interviewee to spend time describing the effect these diagnosis' had on his core existential beliefs about himself, his family and his role in life. Frank(1998)⁽¹³⁾ is quoted by Findlay for encouraging listening rather than fixing, promoting health care professionals to listen to each individual's story empathetically, encouraging us to truly listen as part of helping the person work through the situation they are in.

Method

This research is a phenomenological study of life experience, using open, non directive questions and 'really listening' with both curiosity and compassion to what was being said; my participant was encouraged to describe his experience including his own reflections of that experience in a non-judgemental atmosphere. I did return my participant to actual lived events at times as he had a tendency to intellectualise and rationalise his experience at times. Hopefully I set aside any assumptions, beliefs, pre-conceptions and theoretical assumptions in order to listen to another's experience. It is a privilege to share someone's personal experience as there is an ethical responsibility to respect their privacy and dignity. Towards the end of the interview I did highlight specific areas to expand upon and have reflected on this and the possibility of my own interest in these areas as there is a critical balance between respecting the boundaries of the participant and establishing a direction to the interview.

I adopted the recommended simplified variant of the phenomenological analysis method developed by Wertz (1983)⁽¹⁴⁾ that outlines 7 steps in analysis:

1. Aiming to empathise
2. Taking time to dwell
3. Turning towards meanings
4. Reflecting

5. Creating themes
6. Illustrating interpretations
7. Engaging reflexive analysis and evaluation

The participant is a friend and colleague of mine and I hoped that having this established relationship was positive in terms of developing rapport and making him feel relaxed and able to talk freely, although I was aware that this interview would be quite different if carried out by someone else; some studies highlight that stranger interviewer can often be more liberating as there is no ongoing relationship. The interview took place in my home and we worked together on the partial transcript of the material later in his home (before he was ill) ; this allowed further discussion of the interview material. He asked me for my comments after the interview and I did make a few brief comments , I particularly commented on his use of language at time which he found very interesting as he hadn't been aware of this at the time.

R's Story

At the age of 55 years, he experienced movement problems on an outward bound school trip; he woke up one morning and his feet were locked. He couldn't understand what was happening and went to the doctors who later diagnosed rheumatoid arthritis. Other difficulties relating to movement and stiffness developed during a two and half to three year period so that at 58 years old he went to see a Consultant who diagnosed Parkinson's as soon as he entered the room. The later diagnosis was less of a shock than the first; in fact by the time he went to see the consultant he had an idea himself what was wrong because he had developed a tremor and restrictive movements, the Consultant only confirmed what he already knew.

The diagnosis of rheumatoid arthritis at 55 years old made him feel 10 years older:

"I felt like an old man all of a suddencatapulted into old age and that wasn't where I was going" and "it was life changing at the time"

although the symptoms responded to medication he had further problems and by the time he received his second diagnosis of Parkinson's he felt that

"it wasn't fair"

and he found it difficult to look for the positive (as he usually did) when presented with problems and he experienced depressing thoughts:

"I think lots of people suffer depression with chronic disease because there is no way out, you are not going to leave it behind.....even though my natural inclination is to look for positives and solutions "

However, it was difficult to be positive as it altered how he saw himself :

"my persona".

He had always seen himself as sporty and fit but now he couldn't hold a squash racket; he couldn't grip and when he tried to play it hurt and he dropped the racket. Not only was it a change to his

persona it was a change to a large part of his social life that had provided release of tension from work:

“my initial thoughts were that when you keep yourself fit it shouldn’t be like this....I had looked after myself”

he likened it to a non smoker having a diagnosis of cancer

He felt the news he had rheumatoid arthritis came ‘out of the blue’ and was ‘a shock to the system’:

“I was pretty much on my own....you can have had depressive thoughts.....I went back home and went to bedI didn’t know any thing about it.....there is a comfort in curling up under a duvet”

He found it difficult to tell people about it. He didn’t tell anyone in advance he waited until he met people but said that it felt as though he was talking about someone else:

“maybe because I didn’t want it to be me”

He told his ex wife first as he still has a good relationship with her but put off telling his children as it challenged the view had of himself as a father. He was proud of the role he had as a father and didn’t want to tarnish that. He wasn’t as strong as he had always been and that affected how he saw himself and was anxious that would affect how they saw him. He was worried that he would have a diminished role in their lives.

He wanted to keep on working as his professional role provided mental stimulus, a strong sense of self esteem and identity as well as an extensive social network. Working as an Educational Psychologist can be a very rewarding job as schools are usually very pleased when a psychologist goes into school and the staff grateful for the support, help and advice they receive. It is a role that enables the psychologist to feel needed and helpful, fulfilling responsibilities that are usually appreciated by teachers, children and parents.

He didn’t want anything in his life to change and there was a sense of him externalising the diagnosis of his conditions as something separate from himself and how he viewed himself. This is an ongoing theme in Dorothy Rowe’s books particularly ‘Depression the way out of my prison’⁽¹⁵⁾

Findings /Analysis

My overall aim is to bring to life my participant’s lived experience-what is it like to be him? When listening to the recording and reflecting on the content of the material it is clear that certain themes present themselves throughout this interview:

Existential aloneness, lack of connectedness with others

Image of self and relationships with others

Our own needs and the needs of others

Independence/Dependency

External/ Internal

Existential aloneness, Lack of connectedness with others

During this interview R got back in touch with the emotional experience of being told he had Rheumatoid Arthritis, there are a few quiet poignant moments during the recording when he reconnects with that experience. This comes as quite a surprise to him as he has not had any opportunity to talk about it in this way. He talks about how he came home and took comfort under the duvet, the depressive thoughts that come into his mind and fear of what life will be like; the unfairness of such an illness when he has always been fit and healthy. When I reflected and said 'a lonely place to be' he replied:

"I hadn't really thought of it before" and went very quiet.

Irvin Yalom(2008) in 'Staring at the Sun'⁽¹⁶⁾ writes about the existential awareness that presents itself in life, it can appear at significant times such as illness, retirement, bereavement etc

"As we reach the crest of life and look at the path before us, we apprehend that the path no longer ascends but slopes downward toward decline and diminishment. From that point on, concerns about death are never far from mind"

He realised that a lot of his social network was linked to playing sport and how fragile those links were without the regular structure of playing racket ball; this was a further loss in his life. The realisation that a significant number of his social contacts were bound up with playing racket ball and without that common interest those contacts would reduce and change.

Self Image and Relationships with others.

How other people would see him and that it would be better to explain to them the nature of his illness rather than let them create fantasies about it for themselves.

R was very aware that others could see his tremor and restricted movements and rather than leave them with their own thoughts about him, he wanted to tell people about his condition. This links in with theories about how we see ourselves and how much this is through the eyes of others. As he had worked in the same place for a number of years and had good relationships with colleagues this was helpful to him and others in understanding the situation as people had started to notice changes in his physical body. His work involved visiting schools, talking with teachers, children and parents so explaining his condition became a frequent and familiar conversation.

How his children would see him was a concern because his core role as a father was linked to being physically fit and healthy, therefore vital and vibrant in his children's lives. The illness made him feel slower less vibrant and he was anxious that this would affect the way in which they saw him and related to him. He had been anxious about explaining the situation to his children as he didn't want anything to challenge the view he held of himself as a 'father' and the view he hoped they had of him as a 'protector'. This role and image as a 'father' is the

most fundamental core construct R holds about himself, therefore he didn't want this to change or diminish in any way.

He had felt 'fit, healthy and vital' able to cope with whatever life throws at you but now doubts about that crept in and he was more vulnerable. He holds a belief that being physically fit and healthy and strong helps you cope with emotional issues as well. He saw himself as pro-active, not waiting for problems to build up and now he was worried that his responses would be much slower:

"my role as a father is much closer to the core than my persona as a sportsman, fit and active".

He asked his ex wife to go with him when he received a second diagnosis of Parkinson's, it was much less of a shock than the first diagnosis. Although he felt it very unfair in terms of life chances he felt stronger and was more focussed on fighting 'IT'.

I asked which part of him was important and he explained it was being a father, he felt he had carried out this role well. He is proud and pleased as the way in which his kids turned out; it is the most important thing he has done and the illness threatened that.

Social relationships were based on a shared sporting activity and therefore with reduced agility and mobility he could not retain the frequent visits to the gym for games of racket ball. Although he has managed to retain some aspect of this in his life it has changed and some of the social relationships do not exist in the same way. This highlights the differing aspects of friendships, how some are formed through work associations, others through shared activities, others where the activity doesn't matter only the person; how some last over long periods of time and others are short but they can vary in terms of emotional connectedness. It highlighted how friendships through sporting activities can be based solely around the activity and cease to continue if the activity ends.

Our own needs and the needs of others

R's daily life was organised around his work, leisure time around his sporting activities and his family. Working with children, families and schools is demanding but rewarding and creates a sense of 'being needed' 'being helpful and useful'. R's career was focused on problem solving, looking for solutions and being positive, this wasn't just a professional working theory /ideology but a very personal one that he used in his personal life as well. R was very thorough in his practice as a psychologist and felt that he liked to provide recommendations and strategies for adults to use so that situations would improve and therefore become more positive. In doing this he had a need to be helpful and respond to the needs of others. In the same way he carried out his role as a father in responding to the needs of his children, helping them with problems and being a protector.

This diagnosis challenges R's script as he has now become aware of his physical limitations and therefore his own needs in terms of support and help. He recognises that he needs help in cleaning his house and organises that; he also acknowledges that he can claim the disability allowance and organises someone to help him complete the forms to make a claim. However, the underlying inevitable physical deterioration and increase need for help and support is somewhere in the future. I remembered an earlier conversation when spoken to R about the

Parkinson's group meetings that were advertised in the local paper but he did not feel ready to be in company with people who were further down the road in terms of their condition. This had been highlighted by Findlay in her study when she quoted Ann as saying:

"No, I don't need to be in the company of people who are much further down the road.....I'll cross each bridge as I get there. Anticipating too much is not helpful" p165⁽¹⁷⁾

Independence/ Dependency

The illnesses stimulated fears of dependence in his role as a father he had been a protector, he became very uncomfortable with the fear of losing his independence:

"I don't like to be dependent.....not in my nature".

But quickly went on to say how this has changed and how his children are quite happy doing things for him and he can still do some things for them.

He talked about the importance of the medication in stabilising his condition as this enabled him to 'feel more in control', make decisions and start to look for the positives in his life, new things to do or things that he could still do. However, he went on to explain how this could easily be challenged if the medication wasn't quite right and his movements were more frozen or he hadn't slept well the night before. On these occasions he would experience more frustration and some disabling thoughts about the future and what would happen to him.

External/Internal

A constant theme throughout this story is the way in which the chronic illness is external to the core of R's life and personality; he seems to have positioned it as a problem to be solved and is constantly searching for solutions to the many problems that occur. He refers to his chronic illness as 'it' and when we talked about this he said that was because he didn't want it to be part of him; it was a way of avoiding internalising, he was maintaining some separateness by keeping the illness external.

Discussion

Links with previous research

Depression

As indicated in the literature review a significant amount of the research by Findlay and others cited by her e.g. Crossley 1992, Charmaz 2000, Toombs 1992/5, 2001)⁽¹⁸⁾ indicates the level of depression experienced by people who have chronic illness.

As a psychologist R was aware of this and made reference to this during his interview; however he also has strong beliefs in 'Positive Psychology' problem solving and finding solutions that he applies to his own life;

"It is my nature to look for the positive"

However, Dorothy Rowe writes in ‘Depression the way out of your prison’ that we are brought up to believe that if we lead a good life and do the right things we will be rewarded and that when this doesn’t happen in life we experience disabling depression:

“whatever the kind of disaster, it shows you that there is a serious discrepancy between what you thought you, your life and your world were and what they actually are. This serious discrepancy is a threat to your meaning structure.. You feel that as a person you are falling apart, shattering, crumbling, disappearing, that is being annihilated”¹⁵

R felt that the diagnosis wasn’t fair, he had led a healthy life and kept himself reasonably fit, and therefore he didn’t deserve to have these conditions that suddenly made him feel old. This confirms the findings of Dorothy Rowe, she writes about how we are brought up to believe that we will be rewarded for doing the right things in life but how this doesn’t translate into everyone’s life experience.

There is a change in R’s world due to the dual diagnosis that he frequently refers to as ‘IT’; he doesn’t feel as though he has as much control over his life and he struggles to maintain his fundamental positive philosophy towards problems in life. I reflected back to him the use of the word ‘IT’ and he acknowledged that it was his way of keeping illness at a distance ‘out there’ and not part of him. I also reflected back the use of the words ‘You’ and ‘Your’ that are also used in a similar way to depersonalise and keep emotions and feelings at a distance.

R wasn’t aware of these words and the powerful use of language in this way but when we discussed it he acknowledged that it was a way of keeping his illness at a distance and therefore he was more able to cope. This could be taken to therapy, I recognised it as a defence and it was my place to recognise it, bring it into our experience but then leave it as it could be disabling without therapeutic support to explore this further. I was aware of that critical balance/ decision between the interview direction and the participant’s boundaries.

R wasn’t aware that he had used the word ‘IT’ throughout the interview but when we talked about this he recognised that it was his way of trying to keep separate and distant. He explained that if he could manage to keep it separate it was like having a ‘problem’ to be solved which is his preferred way of looking at situations and managing them in his life. In this way he could manage to use familiar skills that he had found helpful in his life and maintain some positive mental health.

He talks about how the relationships have changed over the last few years and how his children have grown to accept some of the physical changes and that they cannot do the same things together as they used to do. Medication had helped so that he has been able to adapt to the changes in his body and find new things to do; he has re-connected with his problem

solving perspective and is now able to make some changes. His position and views confirm some of the earlier research as he does not want to be a member of the Parkinson's group and as indicated in the study he talks about maintaining as normal a life as possible and denying the condition exists or visualising it as a problem to be solved.

Some of R's experience can confirm the earlier suggestion from research, by Findlay, in her study of Ann's experience of a diagnosis of Multiple Sclerosis that the personal story may be a shared social story.

There are some similarities in the stories :

"the relief when the diagnosis is given"

"the desperate feeling of unfairness"

"the need to protect others particularly children"

"the struggle to lead a compartmentalised existence while striving to continue her normal (i.e. previous) existence"

"preserve the illusion of her old normality for as long as possible"

"coping with the loss of hobbies and skills"

"does not want to be revealed to herself as a multiple sclerosis sufferer through the eyes of others"

Reflexive analysis ...how I impacted the research

I was aware of my position as the interviewer in this interaction, and how I may have influenced the course of this interview as I wanted to explore the emotional experience of receiving such devastating news and how it felt to take comfort under the duvet. I introduced the concept of his own needs and asked if he was aware of his own needs that day. He explained that he was more focussed on how other people would react, especially his children and said that he would find it difficult to accept emotional support.

He described himself as:

"a bit stiff emotionally" and

"I always thought I could do with a bit more emotion"

But then went back to talk about how:

"YOUR vulnerability is more apparent"

I felt that from a TA perspective R's behaviour and thinking are from 'a very adapted child' ego position.....very well behaved....doing the right thing.....keeping the rules etc. However, from my own life experience and observations I feel most people who do well at school and get all their strokes from the academic environment will develop a strong adapted children

ego state. The education system (until recently) has emphasised logic and reason and academic success; there have been some changes with the introduction of 'Emotional Literacy' in more recent years.

Ian Stewart describes six adaptations in his book 'Personality Adaptations' as a guide to human understanding and personality. R could be best described as 'Schizoid'; he is kind, supportive and respectful of other people's space. Feelings are his most vulnerable area:

"the way to make contact with them is by addressing their behaviour....you can best do this by imitating contact and bringing them out. The next step is to invite them to share their thinking; then get them to bring their thinking to closure by taking action to get their needs met. Avoid focussing on feelings, since feeling is where they tend to get stuck" p16

TA theory offers more understanding of the 'Schizoid' personality adaptation and suggests that the expectation conveyed by parents to the child would have been 'Be Strong' i.e. disown your own feelings and needs. To avoid the pain of not getting needs met the child feels numb and makes an early decision to take care of them self. However, chronic illness challenges this belief as it is more difficult to cut off from feelings and certainly more difficult to take care of yourself and remain independent.

My interest and previous reading about depression may have influenced the direction of this interview as R is less comfortable talking about emotional issues; I was interested in his thinking that 'life wasn't fair' and that he had sought comfort under a duvet when he was given the diagnosis and did return to these points for further discussion whereas I feel that R wanted to focus the normality of life, positive thinking and that life gives us problems to be solved. He depersonalised a lot of the language and I brought the focus of attention back to emotional interests.

Usefulness of the study/ limitations/ problems encountered/ ideas for future work.

The advantage of phenomenological research is in its ability to capture the detail and richness of the lived experience through active listening and gentle encouragement that enables the participant to talk about their experience in their own time, using their own language and feel that the other person genuinely wants to understand their experience. The study is a narrative of daily life as well as an analysis of deeper existential issues.

The study confirms the main themes from earlier research and highlights the significance of the rapid rate of change and disability influences individual coping styles as well as the psychological make up of the person and the availability of support available. I had to work at not allowing my presuppositions and assumptions to influence this interview; I found it limiting not to explore the emotional internal life in more detail as I had to balance my own interest with respect for my participant who I felt was holding on to a positive belief and some normality in life. It was not appropriate for me to challenge his beliefs only to explore and understand his life experience.

There are limitations to this study in different ways, initial limitations and more significant limitations that I became aware of more recently. Initial limitations were mainly due to R not having the opportunity to express his thoughts and feelings in a therapeutic interview before. He had been on a Counselling course recently and found it challenging and had talked about his preference for cognitive behavioural and solution focussed therapy as he is much more comfortable talking about thoughts and solutions than getting in touch with his emotions. I also felt that he was 'in a sense' holding himself together to retain a positive outlook on life and as he had just retired he had more energy and was optimistic about the future.

However, more recently his medication had to be changed and although the dose was to be gradually increased his condition deteriorated rapidly due to lack of dopamine. When I spoke with him he said that he felt bad both physically and mentally and felt 'scared' as he couldn't take care of himself. Any simple physical tasks such as getting dressed were difficult and taking a long time, eating was slow and difficult and his family had commented that he was losing weight, also he couldn't manage to clean the house or sort out mail and bills. This was a rapid deterioration in his physical and emotional condition and confirms earlier research that commented on the rate of change in disability being a factor in depression. He recently was admitted to hospital due to stomach pains and is awaiting the results of tests. Both his children have spent time with him caring for him which will have an effect on his relationship with them. In fact, when I recently visited he did say that he felt closer to his son than he had previously done.

Social contacts have become more limited as when the Consultant changed the medication he also said that he couldn't drive therefore he was restricted to public transport and as he felt so unwell couldn't manage that. Friendships that were based on the Leisure Centre and playing racket ball have slowly fallen away and even the friendships and attachments from the work based environment have lessened. Therefore, there is more reliance on family members who do not live locally.

The interview would be very different at this present time as I feel he is more in touch with his emotions due to the sudden deterioration in his condition. This has impacted upon me as a friend as I know that I respected his position during the interview when I felt that R was similar to Findlay's comment about Ann who was 'reclaiming her identity through living a 'normal life' at present. But everything has changed.....with medication his condition may stabilise and there may readjustments again and with that more optimism and problem solving. However, he was recently admitted to hospital with stomach pains and had to have two emergency operations for a blockage in the intestine. This was a great shock and he was given little time and no choice about this as there was a significant risk that the bowel could twist and burst. He now has a stoma fitted which may be reversed in 6 months time but at the present time he is very weak, fragile and vulnerable. When I visited him after the operation he said:

" you know the interview we did well it would be a very different one now!!"

References:

1. Sir Ken Robinson (2007). 'Schools Kill Creativity' Video on TED.com
2. Findlay. L (2003). 'The intertwining of body, self and world. A phenomenological study. Journal of phenomenological psychology.
3. Chamaz (2000). 'Experiencing chronological illness' The handbook of social studies in health and medicine . London Sage 277-93.
4. Crossley (2000). 'Narrative psychology'. Theory and psychology 10(4) 527-546.
5. Kleinman (1988). 'The illness narratives: Suffering, healing and the human condition' New York Basic Books.
6. Reissman (2003). Performing identities in illness narrative. Qualitative research 3(1) 5-33.
7. Parkinsons uk.com
8. Menleson, Dakof, Skaff (1995). Journal of Personality v.63 issue 2.
9. Brown, McCarthy, Gotham, Marsden (1986). Journal of Medicine 18 49-55. Cambridge University Press.
10. Townsend, Wyke, Hunt (2006). Journal of Chronic illness v.2.no.3.
11. Charlton & Barrow(2002). Health and Social care in the Community v.10 issue 6
12. Dahlberg (2008). Reflective lifeworld research 2nd edition. LUNDI Sweden Studentlitteratur.
13. Frank (1998). 'Just Listening'. Families, Systems and Health 16(3) 197-212
14. Wertz (1983). 'Analysing the moments of qualitative data analysis'. Journal of phenomenological psychology 14,197-241.
15. Rowe. D.(2009) 'Depression the way out of my prison'. Routledge. Sussex.p.109.
16. Yalon. I.(2011) 'Staring at the sun' Piatkus-Little Brown Book Group.
17. Findlay. L (2003). 'The intertwining of body, self and world. A phenomenological study. Journal of phenomenological psychology.
18. Toombs (1992;95; 2001). 'Chronic illness: from experience to policy. Bloomington& Indianapolis: Indiana Universty Press
'Phenomenology &Medicine' Dordrecht, Holland Kluver
Academic Publishers.