Qualitative Research in Rheumatology: A Personal Perspective

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Introduction

As the title suggests, today's presentation draws on my personal experience of using qualitative research in rheumatology. However there is more than one 'personal perspective' woven through my presentation. I will also draw on the personal experiences of a number of people who live with chronic rheumatoid arthritis.

Two years ago at the NZHPR conference here in Rotorua I presented a paper entitled “Exploring the realities: the lived experience of chronic rheumatoid arthritis” (Roy, 1996). The paper was based on a single participant phenomenological case study I had undertaken in 1995. Today’s presentation builds on this work, and is drawn from my current research study that explores the question “what is the nature of the phenomenon living with chronic rheumatoid arthritis?”

What I want to do in this session is to consider:

• how I came to ask this question,
• What I am doing to seek an answer,
• why I’m doing it this way,
• And finally, what I hope to achieve with this research.

I do this as a way of illustrating what I believe are the benefits of using qualitative research methods to answer some of the questions that are important in rheumatology.

To begin with however, I thought it may be useful for any of you not familiar with the term qualitative research to clarify its meaning. Following this I will outline some of the advantages and disadvantages of qualitative research and provide some tentative answers to the question, 'why qualitative research in rheumatology?'.

What is qualitative research?

A simple definition of qualitative research is:

“Research that is aimed at the discovery of meaning rather than cause and effect. [As in quantitative research]. Methods used are more subjective than empirical.” (Roberts & Burke, 1989, p. 367).

Qualitative research focuses on understanding human actions and experiences within the context in which they occur.

It is also important to note that “qualitative research is neither a pre-cursor to ‘hard’ science nor a way to produce insightful quotations to make quantitative results more human”(Quandt & Arcury, 1997, p. 274)

Of course these are very simplified definitions. What is important to realise is that qualitative and quantitative research have different philosophical underpinnings. It is
beyond the scope of this presentation to delve in to these differences. Suffice to say that both qualitative research and quantitative research offer a range of methods that are valuable in answering questions that concern us as health professionals and as human beings. The challenge to anyone contemplating a research study is to choose a method that is going to best answer the question they are asking.

Qualitative research is an ‘umbrella’ term that encompasses a number of different research methods. For example, ethnography, grounded theory, action research, and narrative analysis, to name but a few. I am using hermeneutic phenomenology to guide my research and I will discuss this in more detail later.

These different types of qualitative research have methodological differences. Sometimes it is difficult to differentiate between them. Therefore it is important for any researcher to articulate the research method used and to use the stated method consistently throughout the research process.

Qualitative research has been used in human inquiry for many years, with its contemporary origins in anthropology and sociology. In the last 15-20 years researchers have recognised the value of this method of inquiry in answering many questions of importance to nurses and nursing knowledge. Questions that are not easily or satisfactorily answered using quantitative research methods. It appears that there are similar moves happening in physiotherapy, occupational therapy, and medicine.

So why is there this growing interest in qualitative research?
I can only really answer this from a nursing perspective, but I suspect there are parallels in other disciplines as well. In nursing the interest stems from the congruence between qualitative research methods and the underlying humanistic ideology of the profession. Nursing today contains elements of commitment and patience, understanding and trust, give and take, flexibility and openness (Paterson 1978, cited by Holloway & Wheeler, 1996). There is much at the centre of nursing practice that can not be quantified. Furthermore, to decontextualize nursing care is, in many instances, an anathema.

**Advantages of qualitative research**
- Qualitative research is good for study of beliefs, behaviours, and experiences
- It gives in-depth knowledge of participants lives (compared with narrow focus on specific variables)
- In qualitative research participants use own words therefore researcher more likely to understand detailed meanings attached to behaviours, beliefs and experiences
- The intimate relationship in qualitative research between participant and researcher provides the opportunity to understand complex relationships and causal pathways
- Qualitative research captures the range and variability of experiences, beliefs and behaviours
- The process of qualitative research, although systematic and rigorous, is inherently flexible which allows researcher to follow insights that arise during data collection/analysis
Disadvantages of qualitative research

- samples small, purposive therefore caution about claims of generalising the results (transferability an appropriate claim)
- time consuming - preparation and analysis times similar but data collection and writing take much longer
- principal investigator needs to be involved in all aspects of process (e.g. can not do insightful analysis if unaware of the context of the interview)

Why qualitative research in rheumatology?

Qualitative research focuses on the experiential dimensions of health and illness. The experiential dimensions are an important aspect of chronic illnesses such as those found in rheumatology. In the August 1997 edition of Arthritis Care and Research Sara Quandt and Thomas Arcury noted the “growing interest in and the demand for the use of qualitative methods in arthritis research” (1997, p. 273). They identified some specific areas in which qualitative research might provide valuable knowledge:

- To better understand how people experience arthritis,
- How they cope or manage their arthritis,
- Their perceptions of health professionals who provide care for their arthritis,
- And their evaluation of new arthritis treatments (ibid).

(My study encompasses all these areas, although the main emphasis is on the first one - to better understand how people experience arthritis.)

The illness experience pervades all aspects of everyday life for the people who live with it. However, the very nature of everyday life means that much of the experience is hidden. As health professionals our interactions with patients are usually episodic. Consequently it is very easy for us to overlook or to be unaware of the patients’ ongoing, daily, illness experience. Often the focus during our interactions with patients’ is on the disease and its symptoms. Qualitative research provides us with a means to re-focus our attention on the person and the impact the disease has on his/her life. The impact that is manifest in the experience of illness.

In relation to the person with RA it is very easy for most of us to list the effects of the disease such as, pain, fatigue, joint damage and functional impairment. We can probably all discuss the various ways these effects can be assessed and even measured, but how many of us understand what it means to live on a daily basis with pain, fatigue, joint damage and functional impairment? The simple answer is that probably we do not (unless we too suffer from RA). Qualitative research can provide us with knowledge that increases our understanding.

I want to share with you here an excerpt from my research data. This excerpt graphically illustrates one aspect of what it means to live on a daily basis with pain, fatigue, joint damage and functional impairment.

Primrose has had RA for more than 30 years. She is describing what is an everyday activity for most of us and something about which we do not usually even stop to
think. But for Primrose it requires acts of contortion, time, ingenuity, and even an element of danger. That is wiping her bottom after toileting. As she describes it:

> Because of my wrists and shoulders I have trouble with my toileting. I have to manage by making a sort of rope out of toilet paper, it’s not 100% efficient, so that from time to time I get a soiled bottom. I pull a lot of toilet paper off, you need a lot, I get about four thicknesses, and then I fold it over a few times and go front and back. Once you have got the bit of rope, you do your best to go up and down both sides, but you can’t see. I just don’t know whether I’m right or wrong. With one hand in front and one hand behind I pull. According to what my bowel movement has been like, say for instance I had a loose motion, well I can tell from the rope that it’s been like that and then I’ll do it twice to make sure. You have to stand away from the toilet in order to be able to get the rope between your legs. But one of the things I have to be careful with is that to do it I have to bend forward and I’m pretty careful about bending forward. So I stand near the wall and can rest my head against the door if I need to. I suppose I’m used to it now. (Primrose, Int. 2, p. 10)

This excerpt illustrates a number of things. It offers an insight to the difficulties faced in maintaining independence in the everyday activity of toileting for this woman who lives-with-pain and with joints-that-don’t-work-as-well. It raises questions of how the environment might be made safer for this woman. Would a particular aid be useful? It also illustrates the depth of data and the intimate disclosure that can result from an in-depth interview. I do not know about you, but for me this story is much more powerful than reading (or hearing) that ‘x% of people with RA have difficulty in toileting’. It also does more to increase my understanding of the phenomenon living with chronic rheumatoid arthritis. Perhaps it will also affect your understanding.

To return now to my research question:

“What is the nature of the phenomenon living with chronic rheumatoid arthritis?”

How did I come to ask this question?

There were two main reasons for asking this particular question.

Firstly, I was aware of the paucity of studies in rheumatology that focused on the experiences of those living with rheumatoid arthritis. Yet I knew of the important contribution studies such as this could make to nursing knowledge and nursing practice. Fundamental to my research is the premise that understanding the experience of illness as it is lived is a vital part of the knowledge from which expert nursing derives (Walton, 1995, p. 239)

Secondly, and probably most significantly, the question arose from my previous study (Roy, 1995) which explored the experience of one woman living with chronic rheumatoid arthritis. The study confirmed my belief that the effects of chronic illness are experienced not only by the person who has the disease but also by their families.
For example, Margaret (the participant in the study) talked of the ‘embarrassment’ experienced by her children because she ‘looked different’ to other mothers (1:11). She also spoke of the family’s reluctance to have anything in the house, such as raised blocks for the sofa, which drew attention to the fact that she had rheumatoid arthritis. As Margaret talked about these and other issues related to her family I was thinking, ‘Yes, it would be great to talk to them too. To talk of their experience of living with chronic rheumatoid arthritis.’

Although I recognised the ‘ripple effect of chronic illness’ (Dunsmore, 1998) I could not address it within the boundaries of the 1995 study. For the present study I was keen to explore the notion further. Consequently participants in the current study are from one of three groups:

- people with RA
- partners of people with RA
- children (>18 yr.) who have a parent with RA

For ethical reasons, particularly the safety of participants and their families and for me as a researcher, none of the participants are related. (I was aware from my previous research that there is a potential for strained relationships and conflict within families. I did not want this research to exacerbate this.)

In all I have interviewed 25 people (considered a large number for this type of research). In qualitative research random or probability sampling is not practicable. However, there are a number of sampling strategies possible, such as purposive or convenience sampling. Four particular issues guided the sampling decisions in my study.

1. Access to participants, linked with the issue of anonymity (i.e. varied the intermediaries, decreased likelihood of participants being recognised/identity guessed)
2. Reflecting the incidence of the disease (made sense to talk to more women than men in group 1, vice versa in group 2, not so important in group 3 but I was keen to talk to sons and daughters of men and women with RA)
3. Range of experience with the phenomenon (i.e. time since diagnosis ranged 18 months - > 30 years, some of the children had lived with it all their lives others were in their teens when their parent diagnosed with RA)
4. Not every one makes a good informant (therefore need to identify those able and willing to share and articulate their experience of living with the phenomenon, did this through detailed information sheet and talking to them about the type of interviews before they signed consents).

- 11 people with RA, (8 women & 3 men)
- 7 partners, (2 women & 5 men)
- and 7 children (5 daughters & 2 sons, 4 had mothers with RA, 3 had fathers with RA)
What am I doing to seek an answer?

Why am I doing it this way?

I am using hermeneutic phenomenology to guide my research method. Quite simply this means the interpretation of a phenomenon. The term hermeneutics originates from the practice of theologians in interpreting biblical texts. Of rewriting them in a way that was more accessible to the populace. Contemporary hermeneutic phenomenology is informed primarily by the philosophical works of Hans-Georg Gadamer. It offers an approach to understanding the way people experience the meaning of the world and their place in it (Steeves & Kahn, 1995, p. 177). Hermeneutic phenomenology is underpinned by a number of assumptions, four of which I will briefly share:

1. As human beings we experience our world through interpretation and understanding (there is no uninterpreted fact)
2. Understanding is influenced by social context, our ‘world view’, and our time and place in history (historical horizon).
3. Understanding is a dialectical process involving both the interpreter and the interpreted (a fusion of horizons).
4. Language is the medium through which understanding and interpretation occur (linguisticity of understanding).

So what has this meant for my research method?

These assumptions have underpinned all aspects of the research process. The three aspects I would like to highlight today are, the role of the researcher, the method of data collection, and the process of data analysis.

The role of the researcher

In hermeneutic phenomenology the researcher has an active role in, and influence on, the research process. There is no attempt to attain an objective stance. The term ‘researcher-as-instrument’ is often used to describe the role of the researcher in studies such as this. It is not possible for me as the researcher to stand outside the interpretation of the participants' experiences. Indeed the final work will be my interpretation, an offering of my understanding of what is to live with chronic rheumatoid arthritis. Of course my interpretation will be influenced by the dialectical process that occurred during the interviews with participants. There is also the recognition that this interpretation or understanding will be affected by my previous knowledge and experiences as a nurse, as a mother, as a wife, as a daughter, living in New Zealand in the second half of the 20th century. In other words the social context within which I live, my historical horizon. Of course the research participants have also brought with them to the research their own historical horizons and this in turn has influenced my understanding.

Data Collection

The method of data collection has also been influenced. Data collection has involved in-depth non-standardised interviews with the participants. The interviews were audio-taped and transcribed verbatim. These transcripts have formed the text for analysis and interpretation. The interviews were ‘conversational’ in nature and involved the participant and my self in a dialogue about their experience of living with chronic
rheumatoid arthritis. As the interviews progressed my understanding of the phenomenon moved to a new level, as did the understanding of the participants’. I often heard comments such as ‘I’ve never thought about it that way until now’.

Although not the exclusive domain of hermeneutic phenomenology I think it is important to mention here the potential benefit to participants of this type of interview. As well as providing an opportunity to reflect on their experiences and perhaps look at them in a different way, the interview for many participants was the first time they had ever had the opportunity to tell their story. This seemed particularly so for the partners and children. One husband thanked me profusely for inviting him to participate, adding that in the 30 years his wife has had RA this was the first time anyone had asked him about it. Jan whose mum has RA had this to say:

_This is the first chance I’ve had to tell ... (my) story.... I was really excited to be able to tell my story I guess, because it’s the first time (that there’s been a) recognition that there is even a story to tell from any other perspective....It’s really important to be able to put it out there somehow....I think it’s amazing that there are people (like you) ... who are looking at and acknowledging, ... the reality of being a patient, and the effects that that has on all the people around them. I think there is very little being done on the patient and not just the disease. I think the patient’s experience is overlooked a lot of the time._ (Jan, 1:30)

Might I add here that this was a spontaneous comment from a young woman who is not a health professional.

In the literature there are numerous references to the benefits of participating in qualitative research. The process is described as cathartic, providing an opportunity for self-acknowledgement, self-awareness, empowerment and healing (Hutchinson, Wilson, & Wilson, 1994). I certainly consider this one of the positive benefits of participation. As human beings we like to be acknowledged, to be listened to. For those of you who were at the Sydney conference you may recall the numerous calls from people such as Julie Dunsmore to acknowledge the experiences of patients and their families.

Data analysis

The underlying assumptions have also influenced the data analysis. In hermeneutic phenomenology analysis involves working between individual transcripts and the transcripts as a whole. It's a process of moving back and forward asking questions of the text, identifying ‘stories’ and themes that elucidate the phenomenon of living with chronic rheumatoid arthritis. It is this stage of the research that is occupying my time at present. It is time consuming, occasionally overwhelming, but ultimately rewarding. I have some incredibly rich data and I am very excited about the initial outcomes of my analysis.

I thought at this point I might share with you a few of the ‘stories’ from my data. I do this as a way of illustrating the depth and breadth of data that can be obtained in this type of research. I offer it to you primarily in the form that it was presented to me before it came under my interpretive gaze. As well as being an illustration of the type
of data collected I hope that these stories will provide you with insights that affect
your understanding of the experience of living with chronic rheumatoid arthritis.

These 5 stories all show or ‘bring to light’ some aspect of the phenomenon living with
chronic rheumatoid arthritis.

The first story provides insight into the experience of Ivy, a woman with RA who was
transferred to an acute surgical ward following complications to arthritis related
surgery. The move appears to have been made more for the convenience of the
surgeon than the patient and her family. Staff working in this area are more use to
caring for patients with short term acute conditions.

Being in a ward where people came and went ... it was so different [from
being in a ward geared to your RA because nobody there ... knew of my
plight.... The [nurses] didn’t know, and they would say “You’ve got to do
it, you’ve got to get up” and I would say “But I’m not able to” or they
would say “have a wash now” and they would put the bowl of water on
the bed table but I couldn’t get my hand around and [so I couldn’t wash
myself]... it was an accident ward and people came and went ... and the
physio came, but they only came to assess you, they didn’t give you any
exercises to do, ... and the nurses... you didn’t build up a rapport with
them because they didn’t know, [they didn’t understand]. They would say
“Oh you have to have so and so done today” .... they didn’t know that
that wasn’t actually what you really needed, you needed something else.
Or [they’d say] ‘hurry along’ and I couldn’t hurry.... They weren’t geared
for daily constant nursing of you ... they just treated you like a number,
which of course you were when you were in a ward like that with people
coming and going, you are just another person aren’t you, ... Now this is
a really small thing, but this is the sort of things that happened...
... I take
all my medication with food and they would come in with breakfast which
would be fine ... but I would have to wait until they brought around the
pills, [but] if they were busy they wouldn’t bring them around on time....
so quite often I would have cold porridge.... It was those things that they
were so busy that they didn’t think about ... they weren’t accepting of
anything that was slightly different.... When I was able to get up and walk
a little bit further, I said to one nurse “Instead of me having to call you
for a bed pan, or to take me to the toilet, how about you put a toilet chair
in the toilet and then I can go myself”. I was trying to save them time and
also to get myself into gear. So she said “yes that’s fine.” So she told
everybody what to do. But then ... I’d go to the toilet and the toilet chair
would be gone. When I said “the chair isn’t in the toilet”, I was told
“Well so what, you’ve got a toilet seat there” ... But I couldn’t use
the toilet seat, I needed the chair”.

However, one nurse was particularly helpful [I would make suggestions]
and she would help me, she helped me to do what I could for myself, and
that’s what I call interested and good nursing. [Her skills] developed in
the time that I was there and she was really very helpful.... When I was
leaving ...I [thanked her] for being so helpful and for all the individual
[attention]. I was very grateful for the little ideas we had, that helped me
get better.... She said “I’ve got to thank you too, because you have taught me patience and tolerance ... we have both learned something”.

I have heard stories similar to this from other participants too. It concerns me greatly because the situation of being admitted to wards ‘not geared to your RA’ is an increasing occurrence for people with RA as specialist units are ‘downsized’ or closed. Of course it increases the imperative to ensure all nurses (health professionals) have a better understanding of the illness experiences of people like Ivy. And to incorporate that knowledge in care planning and delivery. On a positive note the end of the story shows us what can be achieved when nurse and patient work in partnership, each valuing the other’s knowledge and experience.

In some instances living with chronic rheumatoid arthritis means making comparisons to other peoples’ situations. A number of participants compared living with chronic rheumatoid arthritis to living or dying with cancer. Sometimes this comparison is made in times of extreme pain and does not seem so relevant when things are going well. Which is the situation in this first story. None-the-less I could still feel the depth of anguish in Jill’s voice as she told me this story some 15 years after the event:

Within about a year of me being diagnosed [with RA] we had a friend who was dying of leukaemia and I can remember driving down the motorway, going towards the hospital. It was a winters night, it was a horrible night and sitting in the car and I was just so uncomfortable that I thought to myself, ‘in some ways I envy Ruth, at least she is going to die and her suffering will be over. (Jill, 1:)

Partners and children made the comparison with cancer more in relation to watching their loved one enduring the seemingly never-ending suffering associated with living with chronic rheumatoid arthritis. A daughter shared this story with me:

[A couple of years ago] a very close friend of ours developed cancer and I remember after she had been diagnosed Mum really wished it was her ..... and at times that's what I wish too. I wish there was a foreseeable end to it, because I can’t imagine anything more difficult than trying to deal with this continual suffering without, without being able to say well I’ve got a year, maybe two years, I’ve got all these things I need to finish and being able to tidy all of that up and .......... and deal with things. Its more, because in a way it is kind of like a terminal illness, it is.......... I’m sure... its painful, its difficult, but there isn’t an end to it. And with the terminal illness there is all this recognition for everybody else around as well. You are losing a mother, you are losing a sister, you are losing your best friend, but there is nothing like that for this kind of disease and that's really difficult, and its difficult I think being constantly ..... confronted with just a myriad of emotions ... I mean sometimes I just wish she would die. Sometimes I just wish she was better and sometimes I just wish I didn’t have to think about it. (Jan: 1)

This young woman’s story is linked to the isolation she feels as the daughter of a woman with R A, to the lack of support and recognition for her as someone who is living with chronic rheumatoid arthritis. The story also hints at the way society views living with chronic rheumatoid arthritis compared with the almost ‘glamorising’ by society of a disease such as cancer.
The next story is from a man who has been living with chronic rheumatoid arthritis since his wife was diagnosed with RA more than twenty years ago. For him living with chronic rheumatoid arthritis means experiencing tension and guilt about doing something that in New Zealand society is considered to be the responsibility of an adult male, that is providing an income to support his family. In this story Ian shares with us what it means for him to go off to work:

My job entails travelling and I just have to get up and go ...sometimes I'll be away for a week. That is hard going, I have to go and turn my back on the situation.... I find it hard really, but then I need the income........... I find it hard to get up in the morning knowing I am going away... and leaving her at home. I try to plan ahead when I'm going away. ...I try to plan my work trips around everything that she is doing. Fitting around her, trying to take the pressure off all the time. Sometimes I actually do a weeks vegies for her so she won't have to peel them and things like that, and I chop the wood. Fill it all sorted out. Its a bit lucky work wise at the moment, I can take her with me for a couple of days if I go away which takes the pressure off because I don't have to worry about her at home. Its a bit selfish of me but otherwise. I am very conscious of the fact that she is on her own and constantly worry about how she is coping....If she's not too well I don't even like going out of the gate in the morning, but not being a person of independent means I can't not work, that tends to be a frustration, but we are not well off so I can't just give up work and say 'hey lets just... I'll look after you sort of thing'.... So I go away and do my work and think about her, but I suppose I shut off to some degree when I walk out the door, but I don't shut off totally... knowing that at home things won't be all that good. One of the biggest frustration's I have is [having to be] aware all the time and not, not wanting to be quite often. I suppose the frustration really .... is that everything I do I'm very conscious of .... how she may be or may feel, how it might affect her.... But I want to do my own things sometimes as well, not really to have to think about somebody else all the time, the total impact of what I do on another person. Which I guess is quite mean. I go to work and can switch off for a while but its still in the back of my mind, I wonder whether she's got out of bed yet or what she's done. (Ian:1)

There is real tension in Ian's story. He finds it hard to leave his wife, he constantly worries about her, ‘switching off’ only occasionally. At the same time he finds it frustrating to have to constantly ‘think about someone else all the time’.

The final story, like the first, has both positive and negative elements. It is a story of lost dreams, personal costs and paradoxically, personal growth. In this story we catch yet another glimpse of the phenomenon of living with chronic rheumatoid arthritis as Jo, whose husband was diagnosed with RA more than ten years ago, shares what it means for her to live with chronic rheumatoid arthritis.

I think it's quite sad. .... John isn't the person I married and it's not how I ever envisaged our life and if I look ahead to the future, I get really emotional because I think, well, it's not going to be what we dreamed of... and it's not what we dreamed of now, and ... the children have missed out alot. Well we have all missed out in different ways.... I mean [often] he just wants to be by himself, without any noise. He gets home from work,
the last thing he needs is kids clambering at him, asking him questions, wanting this that and the other and so it's definitely taking a toll on the children. I don't dwell on the future very much because it's just a big question mark ... I just generally feel ... I don't feel angry, I just feel sad ... By the time he has got through the day, he has given his all to get himself through the day and he just has had it.... work has been his salvation, ... because it's given him a purpose... but it actually takes everything he's got ...... sometimes he comes home and I think well he's got nothing left to give the family., (Jo:5-8)........

[One thing that has been positive] ... is that I cope better with a lot of different things.... There is also the fact there are people that really need me and who would really struggle if I fell apart, there's that feeling of.... I've got to do it and whose going to step in, John can't do it. Who is going to do it if I don't do it. So there is that extra kind of responsibility, that makes you pull yourself up. Put your shoulders back, grit you teeth and get on with it. I have to be strong. It's just something you develop... something I've had to do. I think... I always lent on him and it's been a kind of reversal of roles, because I lent on him, depended on him for his strength, because .... he is a .... I guess he still is, he was always very strong macho, almost chauvinistic at times, .... And he has had that taken away from him. Yeah. It has it's been a reversal of roles. Although he still makes decisions .... I feel strong, I feel able to cope with things, that I probably wouldn't have, even ten years [ago].... [Another positive thing] from the RA is that its allowed me to see emotion in John. I don't think he would ever have broken down and cried if it hadn't been for this. I don't see it as a weakness, but more human. I might never have seen it in him otherwise. (Jo:1)

But I guess the hardest thing really, in this whole thing is the impact it's had on the family. And family life. That's been the hardest thing. I mean people change anyway. As you grow up, the person you are in your 20's is very different from the person you are in your 40's, I mean it's just life's lesson. Isn't it, and you expect changes but, when you've got a young family and something like this happens,...... I guess I have come to learn that it is like dealing with a loss ......... You deal with it, but it never goes away and it's always there. And the emotions are always there. You start looking at personal costs.(Jo:1:28)

Do these stories offer you a sense of 'seeing' the phenomenon of living with chronic rheumatoid arthritis. Perhaps you are seeing it in a different way. Do these stories help you recognise that in the everyday world much of the illness experience is hidden? Perhaps your understanding is affected, only you will know that, because understanding is something that occurs within each of us.

These stories represent only a small part of my data. I still have much work to do in drawing together the 'stories' and themes and presenting them as an interpretation, a new way of looking at the phenomenon living with chronic rheumatoid arthritis. This is the challenge that is ahead of me in the next few months. I hope that in sharing these stories I have created an interest in my research and in qualitative research in general.
Finally, What do I hope to achieve with this research?

The answer to this is speculative at this stage but I see it having potential in a number of areas.

- Firstly, related to nursing education, which is my current area of employment. I hope that this study will help students in their understanding of the experience of living with rheumatoid arthritis and its implications for families - better equipping them to deal with the real thing in the clinical situation.

- Secondly, just as my understanding of living with chronic rheumatoid arthritis has been (and still is being) changed as I work on this study, this research has the potential to change the understanding of those who read it. It may challenge nurses (and other health professionals) to reflect on their practice and maybe enhance the quality of their care. A strength of study such as this is that it is aimed at making a difference to the practice of individual nurses (Gasquoine, 1996, p. 16).

- In addition, this research has the potential to help people with rheumatoid arthritis and their families.

- Of course for this to happen the work will have to be presented in a way that is accessible to these groups. For most people a thesis is not an accessible format so the challenge for me, as for any researcher, is going to be in making it accessible - something to do with my time in my 'life after a PhD'.

Qualitative research in rheumatology: a personal perspective.

I hope this presentation has shown you some of the advantages of using qualitative research in rheumatology, either as a researcher or as a consumer. I believe qualitative research methods offer exciting possibilities for research in rheumatology and the development of knowledge to enhance the quality of the care we, as health professionals, provide.

Thank you.

Questions/Comments?
References


