

Understanding the conflicts of disability

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ABSTRACT

Purpose

To improve understanding about the experiences and concerns of women with rheumatoid arthritis.

Method

The study used a constructivist qualitative methodology that acknowledged the diverse ways that women with rheumatoid arthritis viewed the part that the illness played in their lives. This paradigm allowed for multiple interpretations of specific issues arising for the women, in particular focusing on the way they integrated the illness into their lives.

Results and discussion

The findings related to the dilemmas that surrounded identity, role and self-disclosure. The paradoxical nature of these conflicts made resolution difficult.

Conclusion

Most women with rheumatoid arthritis showed resilience as their disability altered over the years. The changeable nature of symptoms and the conflict between providing care for others and requiring care was problematic. Covering up symptoms appeared to be a form of denial that was commonly used as a mechanism to maintain normality.

Keywords

Rheumatoid arthritis, disability, qualitative methodology

(NZFP 2003; 30: 35–39)

Introduction

The focus of this study is on women's subjective experience of rheumatoid arthritis related to the illness, rather than the objective features of the disease. An approach centred around function may be useful where there is an ongoing health problem or disability. Allied health professionals tend to use this approach and McWhinney¹ suggested that general practitioners may find it useful. The orientation of which McWhinney

writes highlights the difference between two important concepts in medicine, illness and disease. The general practitioner must understand both: the disease and the response of the woman to the disease. Being the general practitioner of a woman with rheumatoid arthritis often holds dilemmas. The general practitioner may find the reality of the patient's problems so uncomfortable that he or she becomes remote whilst leaving the patient emotionally unsup-

ported, particularly when there are uncertainties and a patient expects firm answers.¹ Patients differ significantly in their tolerance of uncertainty.²

The models of disability

As suggested by McWhinney, this study followed a theoretical framework that used rehabilitation concepts. General practitioners would be more familiar with the medical model of disability than the social model of

disability. The New Zealand Disability Strategy³ relies so heavily on the social model that it is important for general practitioners to be familiar with both models.

The medical model can be represented by the World Health Organisation's first classification of impairments, disabilities and handicaps (ICIDH-1).⁴ This classification has been undergoing review since 1998 and portrays three categories of disability: impairments, abilities and participation (ICIDH-2).^{5,6} Firstly, impairment affects a system or organ within the body, for example, the musculoskeletal system. Secondly, a person's activities may be classified to show abilities and limitations. For example, someone severely limited in mobility may achieve very highly in an academic occupation once environmental barriers have been overcome. Thirdly, instead of only classifying the handicaps that people face, the new classification records people's degree of participation in life, linked with environmental factors or the challenges that face them. Thus the previous International Classification of Impairment, Disability and Handicap (ICIDH1) that perpetuated the negative status of people with disabilities has become a more accurate and liberating document.

The social model of disability focuses on the social and physical environment as the real cause of disability. Many people with disabilities contend that the real causes of disability lie in people's attitudes, in particular discrimination.⁷ Barriers are not only physical, but include transport, bureaucracy, attitudes and communication, the latter being of particular importance to the deaf, blind and those with sensory impairments.⁸

The models of disability and rheumatoid arthritis

The visible appearance of deformity and invisible features such as pain and fatigue in addition to the role of therapeutics made rheumatoid arthritis a good condition to investigate regarding the models of disability and general practice. In this paper insightful literature from disability studies and the social science literature have been brought together with

the medical literature to enrich general practitioners' knowledge of issues critical to understanding women's experience of disability. Other recent studies have their own perspectives. One study⁹ has

examined the experience of women admitted to hospital and has an orientation to inpatient care. Brown and Williams¹⁰ revealed similar themes to this study but this paper intentionally highlights topics not previously discussed that expand the knowledge of general practitioners. An excellent recent New Zealand study⁶ has included reference to ICIDH-2 but does

not come from a general practice perspective. It is the broad multi-disciplinary approach centred in general practice that makes this study different. In association with the implementation of the New Zealand Disability Strategy it is timely to examine the personal experience of disability.

Method

A constructivist qualitative methodology was used to explore the meaning of having rheumatoid arthritis. By this methodology the researcher and the participants aimed to enable people to become more informed by a joint construction of knowledge.

Selection for interview

Women who had the disease were selected for interview from a larger sample of women with rheumatoid arthritis in the greater Dunedin area.^{11,12} The purposive sample ensured a diversity of their demographic and personal characteristics. Ten women were required for data saturation.

Data collection

The women were interviewed twice, two years apart. Interviews were semi-structured and were transcribed. A

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Table 1. Prompt guide for the first interview

Participant's first symptoms of RA.
Course to diagnosis.
Process of diagnosis.
How participant found out knowledge about RA.
Participant's attitude towards knowledge about RA.
How arthritis most affected participant.
Coping – own and others' perception.
Adjusting – own and others' perception.
Effect on work, leisure and care of self and others.
Effect on social life, family life, and sexuality.
The roles of health care professionals, family and friends.
Participant's reactions at the onset/now.
Health care services at different stages of RA.
Visible and invisible characteristics of disability.
Issues that may be gender-specific.

Table 2. Major themes of interviews

The importance of role transformation
<i>Developing a relationship with the illness</i>
<i>New understandings of the world</i>
<i>Reactions to loss</i>
The balance in caring relationships
<i>The difficulty of caring for self</i>
Covering up symptoms and their consequences
<i>'Covering' and 'passing'</i>
<i>Paradoxical behaviour</i>

prompt guide was developed in consultation with the first interviewee (Table 1). Analysis of interviews began after interviewing the third woman.

Data analysis

The methodology for the analysis of data was similar to that described by Corbin and Strauss.¹³ Selected utterances were identified that reflected the way the participants perceived their situation, and observations were made about the segments. At first these selected fragments were small. As analysis progressed, detailed exploration of the emerging themes and construction of underlying relationships coalesced in the data. Care was taken not to develop theory too early. The context of each single interview was essential to understanding the meaning of the actions and events in the life of the participant. As themes emerged in the interviews, a simultaneous process was taking place in data collection, for the themes would generate ideas that would determine which participant to interview next. After six interviews a 'tree' structure began to evolve which connected the data in a way that relationships could begin to be postulated.¹⁴ More direct questions were used in the second interviews where participants were asked to comment on all the issues that had been brought up by all the women in the first interviews.

The trustworthiness of the data

Specific techniques showed that the data complied with the requirements for trustworthiness although it is out-

side the scope of this paper to give further details. A second researcher was employed to undertake independent analysis for triangulation of data.

Results and discussion

This paper will concentrate on only three major themes emerging from the interviews. The themes were chosen on the basis of those that may be most unfamiliar to general practitioners. Other important themes such as uncertainty have been omitted to allow for depth of discussion of these three themes. These themes are displayed in Table 2. The entire research project is available in Varian.^{11,12}

The importance of role transformation

Developing a relationship with the illness

The onset of the illness precipitated a real change in the identity of some women. Some women had a deep capacity for transforming their identity into one that held more meaning. Cassel¹⁵ has also observed this phenomenon in a discussion of case histories: '*Persons are able to enlarge themselves in response to damage, so instead of being reduced, they may indeed grow*'. This transformation corresponded with an important turning point in the course of the illness.

One of the ways by which the women achieved a positive relationship with the illness appeared to be by changing how they perceived themselves and consequently how others perceived them. Meaning, by its very nature, is highly unique.^{10,12} The meaning of illness was not simply related to sickness or disease, but a meaning that makes sense of illness in the entire context of daily life. For example, two women used their personal understanding of the effects of illness and disability in their employment to formally educate the community about the effects of disability, or support others with disabilities. A positive relationship between self-concept and disability has been reported previously^{15,16,17} but these reports remain scarce.

The women had varied primary roles but they all had a strong sense of self and most of them seemed to embrace rather than reject a relationship with the illness. It appeared to take time to develop a relationship with the illness. Those who had the chance to live with the illness over the years, learning how to handle it and how to relate to it as part of themselves appeared to be more confident, more in control and more accepting. The relative short time between interviews – two years – prevented discussion of the longitudinal evolution of coping skills and interpersonal issues apart from one instance that arose by chance. One woman had teenage children and observed how their attitude became more considerate of her disabilities as they passed through adolescence.

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New understandings of the world

The process of learning about the real meaning of chronicity was a gradual process. The family culture particu-

larly and family members' traditions of caring were important. The adjustments were related to transformations that arose from their new understanding of the world. This new understanding was based on a discovery of how much they had taken for granted in terms of functional ability and performance of daily activities. This discovery was sometimes accompanied by wonder as women marveled at the resilience that they had found within themselves. This reaction was variable in duration.

Reactions to loss

Reactions to loss were variable according to the woman's personality and coping strategies. Naturally, the impact was greatest when it referred to an activity that the woman had valued or at which she had previously excelled. For example, one woman who referred to herself as a physical sort of person mourned the fact that she could not participate in sporting activities with her children. Loss was also related to changes in self-image. The impact of having to abandon wearing high heel shoes was mentioned by several women.

The balance in caring relationships

The difficulty of caring for self

One of the principal roles of women in society is that of carer, primarily carers for the family, for children, for parents, for husbands, and for friends.¹⁸ Women in this study admitted when directly asked that they thought about caring for themselves last, and found caring for self difficult. They also found it difficult to allow others to care for them. This was a significant finding for it had implications for the family dynamics of these women.

Women have not traditionally been made aware of their responsibilities to care for themselves. There is a role conflict between caring for others and caring for oneself. The issue is especially significant for women who have an illness that, like rheumatoid arthritis, features exacerbations and remissions. The fact that the degree of disability may be changeable is often poorly understood by society and the bureaucracy that administers welfare benefits.^{18,19} The concept of the balance between being a carer and caring for self requires insight into the disability. General practitioners could make an important contribution by discussing that balance with women.

Covering up pain and disability

'Covering' and 'passing' behaviours

Women adapted their behaviour as they found it necessary to make adjustments. Decreased time and energy as a result of pain was a new factor that needed to be taken into consideration. Perseverance and pride were determinants that interrelated in a complex way to give rise to behaviour that generally underplayed the severity of the women's symptoms. By far the most striking method by which this was done, was by using the processes that have been called *passing* and *covering* by Goffman,²⁰ passing 'as normal', and attempting to 'cover up' disability.

The fact that the degree of disability may be changeable is often poorly understood by society and the bureaucracy that administers welfare benefits

Almost all of the women spontaneously talked about their reluctance to complain about symptoms but none could suggest a reason. Previous research²¹ has suggested that people with rheumatoid arthritis try to cover up their symptoms of pain and fatigue because they perceive that others around them become uncomfortable around those who are ill.

Key Points

- Instead of only classifying the handicaps that people face, the new classification records people's degree of participation in life, linked with environmental factors or the challenges that face them.
- One of the ways by which the women achieved a positive relationship with the illness appeared to be by changing how they perceived themselves and consequently how others perceived them.
- Almost all of the women spontaneously talked about their reluctance to complain about symptoms but none could suggest a reason.
- The paradox of wanting acknowledgment of pain and other symptoms but simultaneously wanting to deny them appeared to be a conflict.
- Resisting assistance was a method the women used to maintain normality and could be seen as a form of denial.

Using these processes could be viewed as a form of denial. Other hypotheses are equally valid. Cassel¹⁵ suggested that conflict arose for an ill person because part of them wanted to behave just like their healthy peers, whilst another part wanted to withdraw to a level of functioning that was less exhausting. Another valid hypothesis is that gender socialisation curtails complaints about their symptoms, rather than feelings of stigma.

Paradoxical behaviour

The paradox of wanting acknowledgment of pain and other symptoms but simultaneously wanting to deny them appeared to be a conflict.²¹ The

women were placed in a real predicament by trying to contend with employment and social commitments with symptoms that were often invisible. Their family responsibilities, in combination with their ongoing fluctuating symptomatology often proved difficult. These issues stem from denial and are crucial for general practitioners to understand, because they have the power to legitimise the women's difficulties. Tack²² advocated educating the women about energy conservation in much greater detail as a practical method of managing fatigue.

Conclusion

Resilience and inner strength were important features of the women's growth incorporating the illness into their lives. The need for social acceptance documented by Locker²³ explained the enormous importance

of passing and covering. The balance between 'getting on with life' in spite of limitations and making others aware of those limitations was hard to achieve. For most women 'getting on with life' means looking after others so it is not surprising that the situation presented a potential problem in family dynamics. Generally the women agreed that they tended not to take sufficient care of themselves. Resisting assistance was a method the women used to maintain normality and could be seen as a form of denial.

Whilst the women saw rheumatoid arthritis as a medical condition, they acknowledged the physical environment as enabling or inhibiting

their participation in activities. These concepts are consistent with the New Zealand Disability Strategy and provide evidence that this docu-

ment is relevant for family practitioners.

The final comment comes from a participant who has lived with rheumatoid arthritis most of her life and confirms the view that we should never make assumptions about people with disabilities:

'...I sometimes think where would I be without arthritis, and whilst arthritis has taken a lot out of my life, it has given a lot to my life, in the friendships, the people I've met, and I guess it calls upon this strength that we have within us, and brings it to the fore.'

For most women 'getting on with life' means looking after others so it is not surprising that the situation presented a potential problem in family dynamics

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