

# “The Experiences of Rural Osteoarthritic Patients”

Project Report

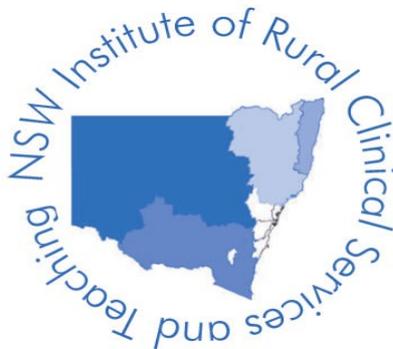
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## **ABSTRACT**

Osteoarthritis (OA) is one of the most common chronic diseases. There has been extensive quantitative research in this area and best practice is well established. Optimal management of OA is often related to self management by patients, therefore an understanding of qualitative research in OA patients can provide an insight into how people make sense of their experiences. This can therefore enhance primary health practitioners' understanding of the choices patients make. This study aims to investigate the experiences of rural OA patients with a particular focus on their experiences with health professionals.

Semistructured interviews were conducted in three rural towns in the Hunter Valley, NSW, that had the following characteristics: population of 1 000 – 5 000; general practitioner/s (GPs); local hospital and public physiotherapy. Patients were recruited by local GPs and physiotherapists and interviewed by a researcher who was not involved in the local community or local health care. Purposive sampling was utilised to identify key informants. Interviews were transcribed and analysed using a modified grounded theory approach using a constant comparative method until thematic saturation was reached. Nine interviews were completed, including six women and three men with an average age of 72 years.

Results include the themes include:

- **Brittle Self Management:** Participants lived their daily lives with stoicism and determination, were capable self managers and were reluctant to seek treatment. This was tempered by desperation when finally forced to seek treatment.
- **Enduring:** Participants adapted and problem solved to maintain a modified independence and to cope with psychological challenges. Internal thoughts and education were identified as sources of support in this process.
- **Effective Primary Health Care Relationships** with GPs were positive, with appropriate access, ability to be heard, being encouraged in shared decision making and effective solutions identified.
- **Surgical Challenges:** Postoperative pain and psychological effects resulted in patients being reluctant to undergo further orthopaedic surgery despite reporting positive outcomes from past surgery.
- **Seeking Therapy Solutions:** Participants chose therapy that was valuable to them within limited choices. This included pain management, education and preventative health care. Pain management was particularly important when self management had failed. Delays in access to physiotherapy were often managed in the interim with alternative practitioners.

Osteoarthritis is a chronic disease that causes long term and significant suffering. Patients are effective self managers, however they require support from health professionals particularly in periods where self management is failing and patients feel like they are in crisis. Effective primary care is being provided by GPs. Significant time delays limit access to physiotherapy. Alternative practitioners play a useful role in providing additional care to OA patients in rural areas, especially when patients are in crisis.

## **INTRODUCTION**

Osteoarthritis (OA) has significant impact upon the quality of life of many older people. Osteoarthritis accounts for half of all chronic conditions in people older than 65 years. Worldwide, it is estimated that 10% of those 60 years of age and older have significant problems caused by OA, with 40% of people older than 70 years suffering from OA of the knee (World Health Organisation and the Bone and Joint Decade, 2001).

The health status of rural Australians is worse than that of metropolitan Australians (Australian Institute of Health and Welfare, 2006). Poor rural health is possibly due to access issues and workforce shortages, but is also likely to be related to the values and attitudes held by rural Australians.

Qualitative studies are especially suited to study chronic diseases, where patient's views are significant indicators of outcomes. Understanding the meaning OA patients give to their reality will improve health professionals' understanding of the choices they make. Improved understanding of the patient's point of view will allow health professionals to be more responsive to their patient's needs. Physiotherapy, along with GPs and orthopaedic surgeons, provide the bulk of care in the management of arthritis.

Of all the chronic diseases, OA has not been extensively studied. This is possibly because it mainly causes morbidity rather than mortality. As the population ages and survival rates from cancer, cardiovascular events and diabetes improves, more people will be living for longer, with more severe arthritis and other co-morbidities (Yelin and Callahan, 1995).

## **LITERATURE REVIEW**

### **Burden of Disease**

Osteoarthritis is a degenerative disease characterised by erosion of articular cartilage, resulting in pain and loss of function, especially in the weight bearing joints (Stedman's Medical Dictionary, 2006). Osteoarthritis has significant impact upon the quality of life of many older people. Osteoarthritis accounts for half of all chronic conditions in people older than 65 years. Worldwide, it is estimated that 10% of those 60 years of age and older have significant problems caused by OA, with 40% of people older than 70 years suffering from OA of the knee (World Health Organisation and the Bone and Joint Decade, 2001).

Of all people with musculoskeletal condition, 42% reported activity limitation, especially leisure activities, social activities, close relationships, community mobility, employment and heavy housework (Gignac, Davis, Hawker, Wright, Mahomed, Fortin and Badley, 2006). Arthritic patients reported 20 days per year where activities were restricted. Of those of working age 18% reported inability to work due to health, while 12% stated they were limited in amount or kind of work they could complete (Yelin and Callahan, 1995).

The economic impact of all arthritic diseases in USA was estimated at 1.1% of Gross Domestic Product in 1992 and is growing exponentially, with an aging population, increased expectations of health, longer life spans and increasing cost of health care (Yelin and Callahan, 1995). Of costs incurred due to arthritis 48% is direct costs of medical care, such as hospital admissions, residential care and medications. Arthritis accounts for 2.2 doctors visits per patient per annum and 0.2 admissions per person per annum, for an average of 7 days. The elderly bear the largest proportion of these costs. The remaining 52% is indirect costs, such as lost wages, which is borne mainly by the 45-64 year age group. Arthritis accounts for 2.2 doctors visits per patient per annum and 0.2 admissions per person per annum, for an average of 7 days.

In a comparison between patients with OA and Rheumatoid Arthritis (RA), patients with OA reported more severe handicaps in social relationships, socio-economic status, emotional well-being and body image than patients with RA (Carr, 1999). Nour, Lafrost, Gignac and Gauvin (2004) found that older housebound adults experience higher levels of pain, fatigue and activity limitations and depression than RA. In contrast, some OA patients are perceived as lazy, especially in the young, as their OA joints are not observable to others (Gignac, et. al., 2006). In addition, of the entire population, OA affects the elderly and women generally more than other groups, therefore heavily impacting on non-paid community responsibilities such as parenting, care giving to the elderly and volunteering (Yelin and Callahan, 1995, Gignac, et. al. 2006).

### **Self Management**

In a study by Singer, Hopman and MacKenzie (1999) the physical ability of OA sufferers declines with advancing age but their levels of depression remain stable regardless of advancing OA. This suggests a strong psychological adjustment or adaptation to the physical disabilities encountered. In contrast Yelin and Callahan (1995) report higher levels of psychological distress in individuals with musculoskeletal conditions, similar to levels found in people with other chronic diseases, but higher than the general population. However Gignac et. al. (2006) found that depression has been shown to be more influenced by pain, socioeconomic factors, social and other psychological resources, sense of control and coping, rather than by disease status. Gignac, et. al. (2006) also found that symptoms affected OA patients mood and made them frustrated and annoyed with others.

In a study of herpes zoster and post herpetic neuralgia, patients identified that they felt their reduced quality of life and pain were minimised by physicians, while physicians identified the

disease as benign and self limiting (Henry, 1994). This perceived lack of empathy for a disease that does not pose a mortal threat may be similar to the experiences of those suffering OA.

Patients with OA reported that their symptoms were normalised e.g. you are just getting older, get used to it, both by themselves and their doctor, especially in older patients. Younger patients also identified longer delays between presenting for treatment and a diagnosis as the health professional assumed them to be "too young to have OA" (Gignac, et. al., 2006).

Osteoarthritic patients reported more pain, stiffness and fatigue than the general population (Gignac, et. al., 2006), with pain elsewhere in the body influencing the experience of pain (Goberman-Hill, Woolhead, MacKichan, Ayis, Williams, Dieppe, 2007). Pain description is also influenced by ethnicity and gender (Ibrahim, Burant, Mercer, Siminoff and Kwoh, 2003). Pain is inextricable from function, adaptation and avoidance strategies reflect this experience (Goberman-Hill, et. al., 2007). Victor, Ross and Axford (2004) found that patients desired pain management and improvements in mobility as treatment outcomes.

### **Interaction with Health Practitioners**

Chronic disease management calls for increased shared decision making between health professionals and patients. In a study of paediatric physiotherapy patients Young, Klaber Moffett, Jackson, and McNulty (2006) found that children reported high levels of satisfaction with their care. However, parents, children and Physiotherapists all reported that other parties were responsible for decision making. During data analysis it was discovered that health professionals and families both influenced decisions to find therapy regimes that were acceptable and manageable, however each party did not feel they had any significant power in the negotiation. It was deduced that this anomaly occurred because each party only noticed what they had to compromise during the negotiations, rather than their successful advocating for other aspects of the care plan. Whether OA patients are involved in shared decision making with their treating health professionals has not been reported in the literature.

Osteoarthritic patient's goals have been shown to be improved pain management and enhanced mobility/functional activity (Victor, et.al., 2004). It seems these goals are often not achieved, as OA patients identified a lack of control over their health and an inability to identify strategies to improve/maintain their health in the future (Gignac, et. al., 2006).

Most OA patients make changes to their lifestyles to try to minimise symptoms (Gignac et.al., 2006). Many were reluctant to use medication, because this was seen as masking rather than curing the disease process and because of unwanted side effects of the medications. OA patients frequently expressed frustration, anxiety and fear about the future, especially in younger patients (Gignac, et. al., 2006).

Victor, et. al. (2004) investigated OA patients' knowledge of their disease and, despite using primary health care twice as much as the general population, only 16% reported that their GP had given the information about OA, 27% reported being given information on managing pain and 12% were given advice on "coping" with daily activities. Despite this, 49% of patients reported they were very satisfied with the care they received from their GP (Victor, et.al., 2004).

### **Optimal medical management of Osteoarthritis**

Zhang, Moskowitz, Nuki, Abramson, Altman, Arden, Bierma-Zeinstra, Brandt, Croft, Doherty, Dougados, Hochberg, Hunter, Kwoh, Lohmander and Tugwell's (2008) study makes 25 recommendations regarding the optimal management of OA, which can be summarised as:

- A combination of pharmaceutical and non-pharmaceutical modalities
- Initial management should focus on self help, such as pacing, exercise and weight reduction

- Advice or referral to Physiotherapist if symptomatic, which may include hydrotherapy, strengthening, flexibility exercises, provision of walking aids, use of a brace, orthotics, modalities
- Appropriate pharmacological interventions including panadeine, non steroidal anti inflammatory drugs, topical cremes, corticosteroid injections, glucosamine, opioids
- Surgical options including joint replacement, preventative osteotomies, fusion when joint replacement has failed.

Ballantyne, Gignac and Hawker (2007) found that some patients who were eligible for joint replacements refused surgery. Explanations for this behaviour included: other pressing health matters relating to comorbidities; other painful areas that are more of a problem than the one being recommended for a joint replacement; coping adequately; fear of surgery; supportive families that facilitate activities of daily living; poor surgical outcomes of friends and family; physicians not initiating discussion of the subject or encouraging patients to delay as long as possible. Patients who refuse joint replacement surgery may focus more on the past than on the future, as expectations of a positive outcome is a key driver in the decision to consent to surgery (Vankatarene, Gignac, Mahomed and Davis, 2006). Decisions as to whether to have surgery or not is related to quality of life perceptions rather than pain (Ibrahim, et. al., 2003). For example, some ethnic groups are at risk adverse with their health and are reluctant to undergo joint replacement therapy due to fear of the small risk of adverse complications (Soucheck, Byrne, Kally, O'Malley, Richardson, Pak, Nelson, Suarez-Almazor, 2005).

Orthopaedic surgery has a role to play in the management of OA patients. In a qualitative study of patients undergoing Total Knee Replacement surgery for their OA, Marcinowski, Wong and Dignam (2005) found that patients were optimistic and focussed on being an active participant in making a better future for themselves. Patients were not always realistic in their expectations but were actively involved in moving forward, even if this meant moving forward at a slower than expected pace. Sometimes this involved accepting help from others, which was acceptable to patients, especially in the immediate post operative phase.

Despite joint replacements being shown to be highly effective therapy for OA (Zhang, et. al., 2008), findings of qualitative studies show ongoing pain and immobility that has not been identified using quantitative studies (Woolhead, Donovan and Dieppe, 2005). Woolhead et. al., (2005) found that, six months into their postoperative phase, patients were still suffering pain and disability, despite describing the outcome of their joint replacement as very good. Most patients described improvements in mobility, pain or both. Most believed that their improvement would continue despite the time already lapsed since surgery. Some patients expressed disappointment that it was taking them so long to recover and were rationalising their situation as being affected by co-morbidities.

Osteoarthritis is a disease that inevitably progresses, despite the best practice efforts of patients and health professionals. Zhang made recommendations regarding the importance of education to enhance self management, specifically hydrotherapy, strengthening, flexibility exercises, provision of walking aids, use of a brace and orthotics. However, Victor, et. al., (2004) found evidence of unmet needs for information and support in patients suffering from OA despite having high usage rates of primary health care services. Whether patients seek significant intervention from alternative practitioners has not been reported in the literature.

### **The Role of Alternative Practitioners**

Osteoarthritis patients may access alternative therapists, with or without the recommendation or knowledge of mainstream health professionals. Some potential explanations reported in the literature for patients seeking out alternative therapists can be found in the case of Gilda Radner, who was suffering from ovarian cancer (Hunsaker Hawkins, 1992). Initially, she sees both mainstream and alternative health professionals. She complies with the mainstream

treatment but seeks out the alternative therapists as well, as she perceives them to be more attentive, more personal and more hopeful than her mainstream health professionals. Despite following the therapeutic recommendations, physically and psychologically, her condition continued to deteriorate. Dissatisfaction with her prognosis led to her withdrawing from mainstream treatment and continuing with her alternative treatment. This case shows that poor prognosis can be met by denial from the patient and subsequent doctor/therapist shopping for a more positive interaction, regardless of the unchanged disease progression.

### **Rural Health**

The health status of rural Australians is worse than that of metropolitan Australians (Australian Institute of Health and Welfare, 2006). In a Canadian study of a rural community, 20% of those over 17 years of age reported back and neck pain or OA (Thommasen and Zhang, 2006). This is significantly higher than the 10% over 60 years of age reported by the World Health Organisation (2001). Further, it was found that more coexisting chronic diseases was a predictor of poor health related quality of life in rural communities. Poor rural health is possibly due to access issues, workforce shortages and decreased socio-economic status (Australian Institute of Health and Welfare, 2006) but is also likely to be related to the values and attitudes held by rural Australians.

### **Qualitative Studies**

Qualitative studies are especially suited to study chronic diseases, where patient's views are significant indicators of outcomes (Holman, 1993). Of all the chronic diseases, OA has not been extensively studied. This is possibly because it mainly causes morbidity rather than mortality. As the population ages and survival rates from cancer, cardiovascular events and diabetes improves, more people will be living for longer, with more severe arthritis (Yelin and Callahan, 1995).

This study will follow a phenomenology theoretical perspective in order to understand the meaning OA patients give to their reality. This will improve health professionals' understanding of the choices patients make. Improved understanding of the patient's point of view will allow health professionals to be more responsive to their patient's needs. Physiotherapy, along with general practitioners and orthopaedic surgeons, provide the bulk of care to in the management of arthritis. The role of alternative practitioners in the management of OA patients is less understood.

### **Research Objective**

The objective of this study is to investigate the experiences of rural OA patients with a particular focus on their experiences with health professionals.

## **METHODS**

This study was approved by Hunter New England Area Health Service's Human Research Ethics Committee (Reference 07/04/18/4.03).

### **Recruitment**

Potential participants were recruited from Murrurundi, Merriwa and Dungog. All three towns are located in the Hunter Valley of New South Wales and have a rural and remote and metropolitan areas classification (RRMA) of 5. All three towns have at least one general practitioner and access to physiotherapy services from the local hospital. There are no private physiotherapists or orthopaedic services available in any of the towns.

Patients were eligible to participate in the study if they resided in the local area, were over 45 years of age and had OA diagnosed by Xray. Patients did not need to have been treated by a Physiotherapist to participate. The study was advertised in the local paper, on noticeboards in GP and Physiotherapy waiting rooms and through snowballing. Potential participants were provided with an Information Pack by GPs and Physiotherapists and/or were asked to contact the researcher directly. Ten potential participants contacted the researcher, all which were eligible to participate.

The researcher contacted potential participants and asked to provide basic information such as age, sex, medications, other treatment (physiotherapy, chiropractor, osteopathy, massage, herbal remedies etc), length of time suffering OA and any other information the participant feels is relevant. The researcher then used the purposive sampling process to select key informants to be interviewed. Nine potential participants remained eligible after purposive sampling was applied. This provided a maximal variation of experiences.

### **Participants**

Nine participants took part in the research. The age range of participants was 45-94, with a mean age of 70. Six women and three men participated. Main types of lifetime employment included manual labour (6), mother/carer (2) and office work (1). No participants held university degrees. Current employment included manual labour (1), carer (1), unemployed (1) and retired (6). Seven participants were currently taking medication to manage their arthritis, while two participants had experienced orthopaedic surgery as a result of OA. Four participants had OA in less than nine joints, three participants had OA in 10-19 joints and two participants had OA in more than 20 joints. Two participants had been diagnosed for less than five years, three for less than ten years and four were diagnosed more than 10 years ago. Self reported severity was mild (3), moderate (4) and severe (2). Four participants lived alone, one with minimal family/friends and three with good support from family. Five participants lived with one person, one participant was a carer and one was cared for. Two participants lived with more than one person and was both a care recipient and a carer. Six participants lived in town, three lived on properties.

### **Interviews**

Local health practitioners were unaware which of their patients were participating in the research. Active informed consent was obtained from all participants using a consent form.

The researcher conducted a face to face semi-structured interview with each participant. Interviews lasted approximately 60 minutes and were audiotaped and transcribed. Transcribers signed a confidentiality agreement.

Audio recordings of interviews were de-identified at the time of recording by using a code name rather than the real name of the participant. Transcripts were therefore de-identified. To

reduce the risk of the participant's voice being recognised, transcribers were selected who reside more than 50km outside the local area.

Computerised transcripts were saved as password protected files. The decoding key and original audio recordings were kept in a locked safe separate from the rest of the data and was only available to the researcher.

Transcriptions were checked by participants for authenticity.

### **Analysis**

Data analysis was carried out using a modified grounded theory approach. Subsequent interviews with key informants were carried out until thematic saturation was reached.

Text was coded and collated to develop concepts, categories and themes. Data was initially analysed by open coding, then axial coding, then by selective coding. A line-by-line analysis generated "in vivo" codes. Similar "in vivo" codes were clustered together to form concepts. Concurrent coding was carried out on a sample of interviews by both the researcher and supervisor. Data was managed in Microsoft Word. Modified grounded theory analysis was utilised to allow the theory to be reformulated as the study progressed.

Semistructured interviews were conducted in order to probe subject's experiences whilst still having a broad structure to guide the discussion and facilitate comparisons.

## RESULTS

A process of 'competent self reliance' was identified as the emerging substantive theory. This described how participants viewed their reality. Within the process five main categories, 'brittle self management', 'enduring', 'surgical challenges', 'effective primary care' and 'seeking solutions' identified participants' experiences. 'Brittle self management' captured how participants lived their daily lives. 'Enduring' described how they adapted their lifestyle and emotions to incorporate their disability and problem solved to minimise their disability. 'Surgical challenges' described the postoperative experiences. 'Effective primary care' described their close relationship with general practice. 'Seeking solutions' captures how participants actively sought out other solutions.

### **Brittle Self Management**

Brittle self management is the category that captured the concepts of 'stoicism', 'self management' and 'desperation'. This category describes how participants were effectively self managing their disease the vast majority of the time, but occasionally self management would be ineffective and participants were desperate for immediate help from health practitioners and alternative therapists. This demonstrated the brittleness of participants self management.

All participants demonstrated 'stoicism' in relation to their pain and reduced function

*"It's part of life. You've got to learn to live with it."*(9)

*"I hate to bother other people"* (5)

*"No matter what I done I can't, I couldn't do it myself with the way my hands were"* (1)

All participants reported many 'self management' strategies that were largely successful in managing their pain and reduced function. These included changing their medications, pacing their activities, reducing their activities and seeking professional help. Most participants had a good understanding of their medications, their side effects and how to utilise them with maximum safety. Most participants were reluctant to seek additional treatment and preferred to attempt to self manage.

*"I have been taking for years, um, supplements, you know. Not actually painkillers but, um, shark cartilage and different things and trying to, you know, sort of heal yourself to help yourself"* (4)

*"yeah, when I feel up to it, it gets done. Not as fussy as I used to be"* (1)

*"After I took them (steroids) for a while, I didn't need them. It was kind of under control again"* (8)

*"I have time to recuperate if I have got pain or whatever"* (2)

If participants did indeed seek additional treatment, this was often associated with 'desperation' as self management had failed. This desperation was effectively communicated to the health professional as participants had confidence dealing with health professionals.

*"I try to put up with the pain as long as I can, because I didn't want to have to do anything about it. If you know what I mean. But it gets to a stage where it is affecting your life, you know, you can't do things because your knees aren't strong enough to do it. You've got to start saying, well, it's time I faced things and started doing something about it"* (4)

*"I didn't ring her again until it got so bad I had to" (1)*

*"It was sort of when it got really bad that I had to go and get something done for it" (7)*

*"I had to admit that I needed help. I had to admit that I wanted to do something about it" (6)*

### **Enduring**

'Enduring' is the category that captured the concepts of "modified independence", 'psychological challenges', 'decreasing role', 'sources of support'. 'Enduring' described how participants adapted and problem solved.

All participants reported that they had "modified independence", either through pacing their activities or accepting assistance from others.

*"Yeah, when I feel up to it, it gets done. Not as fussy as I used to be" (1)*

*"I like being outside working in the yard and garden. I can't do that for long. If I do a day there it takes me a couple of days to get over it" (8)*

*"I can sit down and relax. I can rest if I need to. Or take a couple of panadol... If it doesn't get done today, well, it can wait till tomorrow, type of thing" (9)*

*"I get a bit energetic in the garden, you know.. and you end up getting overtired and then it aches for 2 or 3 days." (5)*

Most participants felt they had 'psychological challenges' through enduring pain or deteriorating functional ability.

*"So over the long term, it wears you down or you toughen up" (6)*

*"cause I came to a black hole. No, I'm not going there" (5)*

*"But no, not sleep in the middle of the day. It would be very easy to go to bed and flop down. But no. I wouldn't do that" (5)*

*"But it can get you down, because of the pain, you know. You think how much longer have I got to put up with this" (2)*

*"I was a little bit vulnerable because I couldn't do the things during the day that I wanted to" (7)*

*"It was no good during the day and it's frightening when you think your head is going to fall off" (5)*

A large factor causing psychological challenges was 'decreasing roles' within the family and/or within the community. For some participants this decreasing role had resulted in social isolation as they were unable to carry out their previous roles within the community.

*"It's very frustrating, but I can't do it (clean out gutters) myself" (3)*

*"Well, it's going to be very sad to move. But, ah, I know we've got to. Because I can't garden, (wife) can't garden and we've got a huge garden. I've been a very keen gardener, it's just mainly the garden. There comes a time, you know... Just got to accept things" (5)*

These challenges were tempered by 'sources of support', often internal thoughts, but sometimes reassurance from education provided by health professionals also tempered the psychological challenges.

*"I always believed it. I was always going to stand alone, solve problems as I went along. Not shove them in the background, solve them. And get on with life" (5)*

*"I gave myself a shake and said "You can't live this way" (7)*

*"But if you have it long term you do have to get tougher because you have to, right. You've got to live with it, so you do have to toughen up" (4)*

*"I don't have time to sit and think about what's wrong with me" (9)*

*"I do have to um, um, give myself a good talking to every now and then. Just to get me thinking positive instead of negative again" (8)*

*"I'm happy with that explanation (about my back pain) and stopped worrying" (2)*

*"yeah, um, cause you're sort of clutching at straws trying to work out what it is. But see when I see the physio she actually told me it was coming from my lower back" (7)*

### **Effective Primary Care**

'Effective Primary Care' is the category that captured the concepts of 'easy access', 'being heard', 'shared decision making' and 'effective solutions'. 'Effective primary care' described participants close relationship with GPs.

All participants reported that they had ready access to their GP.

*"I came home and I made an appointment to see the doctor" (7)*

*"I don't usually have a problem getting into the GP" (6)*

Participants also felt that they had adequate time with the GP, that they were 'being heard' and were involved in 'shared decision making'.

*"Oh, yeah, she's never in a hurry" (1)*

*"He doesn't rush you. No." (3)*

*"Well, you tell her when it gets worse, that you're having trouble" (9)*

*"And I will tell him if I want, err, an Xray or if I want, you know, whatever" (2)*

*"And he said we'll have to give you something for that" (8)*

*"That's why I went back to the doctor and I said to him what I had done (gone to the acupuncturist), and I said, can I have a referral to the physio because I had thrown out the first one" (2)*

*"I just went in and said that, you know, my knees were getting that bad that I just, you know, can't keep on going.. so we decided to go to a specialist" (7)*

*"She's offering me stronger pain relief if I need it. But I'm trying to manage without it" (4)*

## **Surgical Challenges**

'Surgical Challenges' describes postoperative experiences and included 'pain', limitations', 'post operative psychological affects'.

Interestingly, 'pain' was nearly always related to the post operative period. Chronic pain levels were described as aches or discomfort, but rarely as 'pain'. Participants reported that they were unprepared for the post operative functional limitations while they recovered during the first three months after surgery.

*"I would have like to have known what to expect as far as pain goes. Instead of making it feel like it's going to be easy. Cause it's not" (9)*

*"I wish I hadn't let anyone touch my knee" (4)*

*"I was actually bashing myself like this (fist hitting chest) cause I was in that much pain" (4)*

*"What I went through, I wouldn't care if I died" (1)*

Significant psychological affects were reported after surgery as a result of the 'pain' and functional limitations experienced. Participants were reluctant to have further surgery despite reporting a positive outcome from that surgery.

*"It was much better than before I had the surgery...It is worse again now, but I wouldn't have surgery again. Not with the pain I went through (in the three month postoperative period). You'd have to be out of your head to go back for a second one (back surgery)" (1)*

*"They are definitely improving since the surgery,.... but if I don't get them strong before, sort of, Christmas, um, I probably have to have, um, knee replacements. After being through what I've been through (postoperative pain after arthroscopes) I don't know whether I want to do that. I'll think twice about it" (4)*

## **Seeking Therapy Solutions**

'Seeking solutions' is the category that captured the rural challenges of 'access limitations', 'effective therapy' and 'enhanced self management'. 'Seeking solutions' described participants methods of choosing appropriate therapy that was of value to them, within the limited services available to them rurally.

'Access limitations' were apparent mainly with physiotherapy. There was no private Physiotherapist located in any of the towns. Access limitations were related not only to initial therapy, but ongoing frequency of therapy due to lack of leave relief. Access issues resulted in some participants seeking out alternative therapists.

*"I rang and it was about another five weeks before I sort of got in (to physio)... It wasn't very nice because I, I could've, I'm in pain and I'm wanting to work at my knee to fix it up,.... But I've been trying to help myself as much as I could... I just wasn't sure what exercises were best" (4)*

*"Probably once a month, but I haven't seen her (Physio) for a couple of months cause she's been away" (1)*

*"She's (Physio) very busy at present. That's why I've got to wait so long for the next appointment" (1)*

*"It was a Friday when I saw him (GP) and I thought, well, you know, it's Friday. I would have to wait to the following Wednesday to see her (Physio) so I thought... I got into see the*

*acupuncturist the next day and that's why.. It worked the first time. I've seen him twice. The first time it worked, the second time it didn't. And I did actually go and see the physio after the second episode" (2)*

Despite access issues, all participants expressed a high level of satisfaction with the 'effective therapy' they eventually received.

*"All the exercises, I thought she was a slave driver at first, but they (exercises) work" (6)*

*"it (physio) helps, it helps a lot" (1)*

*"it (physio) works for a period of time but you've got to follow up on it" (5)*

*"(The Physio) suggested that I put one rail up (on the stairs). Decided to give me more to hang onto, which has worked very, very well.... I'm safe" (3)*

One outcome from physiotherapy in particular was "enhanced self management". Participants were able to use the therapy they had experienced to better self manage in the future.

*"I got myself an exercise bike, which I've been peddling to try and strengthen" (9)*

*"Yeah, well, a lot of it has to do with mental. How you're feeling at the time too. And as I say, at the moment I'm feeling stronger mentally, so I'm feeling stronger mentally, so I'm going well because I'm pushing myself, doing my exercises and pushing myself through it" (4)*

*"Actually I got a twinge the other day.  
I did these exercises she (Physio) gave me and it's good" (7)*

## **DISCUSSION**

Rural patients suffering OA were found to be affected in most aspects of their lives, including activity limitation, mobility, housework and psychological health. This is similar to the findings of Gignac et. al. (2006), Carr (1999) and Nour et. al. (2004).

Osteoarthritis is a chronic disease which patients have lived with for years. During this time they have been successful in making physical and psychological adjustments, therefore learning competent self reliance.

In the current study patients were found to have 'brittle self management'. This was not a skill that was taught by health professionals, but had been self taught over years of trial and error in managing their own symptoms. Patients showed a certain pride in their ability to self manage, and this may reflect the psychological resource of a sense of control (Gignac et. al., 2006).

Patients were also aware that their self management abilities were sometimes limited. When self management was no longer being effective patients' became desperate for professional help quite suddenly, displaying a brittleness to their ability to self manage.

Physical adjustments in this study were mainly found to be through limiting activity, pacing and lowering expectations. These findings are consistent with those of Gooberman-Hill et. al. (2007).

'Psychological challenges' strategies bear some resemblance to the findings of Marcinkowski et. al. (2005) in patients experiencing a knee replacement. The main difference between the finding of the current study and those of Marcinkowski et. al. (2006) is that Marcinkowski's post operative patients had a positive view of the future. This study found effective psychological self management strategies to be present despite patients' expectations of further deterioration of their OA in the future. Singer et. al. (1999) also reported a strong psychological adjustment occurred in OA patients over many years.

Gignac et. al. (2006) suggests this psychological ability to cope is influenced by pain, socioeconomic factors, social and other psychological resources, sense of control and coping. The findings of this study support Gignac et. al. (2006) in that psychological ability to cope are influenced by a sense of control and coping strategies.

Patients received 'effective primary care' and showed confidence in their ability to access their GP. They felt they received timely and appropriate care which they had an active role in shared decision making. Unlike the findings of Young et. al. (2006) patients in this study were aware that they were active in decision making about their condition. This may be because of the long relationships patients build over many years with their rural GPs.

GP treatment was generally effective in resolving the patients' crisis or reassuring patients that no serious co-morbidity existed. This is consistent with the findings of Victor et. al. (2004). Treatment offered by GPs followed optimal management of OA as described by Zhang et. al. (2008).

Orthopaedic surgery is one treatment option recommended by Zhang et. al. (2008). Woolhead et. al. (2005) found patients described their surgical outcomes as very good, despite then expressing disappointment at how slow their recovery from surgery was. Patients in this study described 'surgical challenges', where they were reluctant to have further surgery due to the short term pain they experienced after their past surgery. Regardless they described their past

surgical experiences as having positive outcomes. Instead of further surgery, patients in this study expressed a preference for self management. These findings add to the findings of Ballantyne et. al. (2007), Vankatarene et. al. (2006), Ibrahim et. al. (2003) and Soucheck et. al. (2005).

If self management failed, patients were 'seeking therapy solutions' such as physiotherapy. Patients experienced significant time delays in accessing public physiotherapy services due to waiting lists and lack of leave relief. This was particularly distressing for patients as when they do seek treatment they are in crisis. Patients reported being forced to self manage while on waiting lists, despite having already admitted that they were unable to do so.

One strategy patients utilised to cope when self management was failing was to access alternative practitioners. Patients were in crisis and desperate for help immediately and so sought out whatever practitioner was available. In the towns studied, chiropractors and acupuncturists were available within the town, so these were the alternative practitioners sought out by patients. Patients expressed a high level of satisfaction with these services for help during a crisis.

Patient education to enhance self management is one of Zhang et. al. (2008)'s recommendations for the optimal care of OA. Despite this Victor et. al. (2004) found patients had unmet needs for education in OA patients despite their high primary care usage rates. This study found that physiotherapy, once accessed, was valued by patients, with a focus on management through exercise and education, both of which enhance long term self management strategies (Zhang, et. al., 2008).

## **CONCLUSION**

Osteoarthritis is a chronic disease that causes long term and significant suffering. Patients are effective self managers, however they require support from health professionals particularly in periods where self management is failing and patients feel like they are in crisis. Effective primary care is being provided by GPs. Significant time delays limit access to physiotherapy. Alternative practitioners play a useful role in providing additional care to OA patients in rural areas, especially when patients are in crisis.

## **RECOMMENDATIONS**

Health Professionals should better understand the significant effort rural OA patients make in self managing their disease.

Health Professionals should better understand that when self management fails, rural OA patients are in crisis and are desperate for help from health professionals.

Health system to acknowledge the central and effective role of GPs in managing rural OA care.

Improve access to public physiotherapy for rural patients requiring OA care.

Acknowledge the effective role alternative practitioners in managing rural OA patients in crisis.

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