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Presumption of perception:

People with arthritis challenge the importance of pain in treatment.

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Abstract

The purpose of this semi-structured interview enquiry was to expand on the quantitative findings presented by Cameron, Andersen, and Speed (2004a, 2004b). They investigated the use of joint mobilization on individuals with either osteoarthritis (OA) or rheumatoid arthritis (RA) and reported that joint mobilization was perceived by most participants to afford improvements in health-related quality of life (HRQOL). Some participants withdrew from the joint mobilization intervention of Cameron et al.'s studies, citing worsening pain. A knowledge deficit existed because Cameron et al. were unable to identify why some people reported HRQOL declines with joint mobilization while most participants reported improvements. In interviews with three individuals of the original cohort, a key theme emerged: That improvements in functional capacity are at least as important as changes in pain. This theme, although consistent among the participants of this study, is in contrast to much of the available literature on HRQOL in people with arthritis. We recommend that practitioners providing health care for people with arthritis take time to determine therapeutic goals with individual clients.

Key Words

Joint mobilization, Arthritis, Health Related Quality of Life (HRQOL)

Presumption of perception:

People with arthritis challenge the importance of pain in treatment.

Pain is a subjective experience, colored by the history and nature of the person experiencing it. Levels and tolerance of pain are as variable as the individuals who experience them. In arthritis, as in almost all diseases, it is not possible to detach the physical or psychological aspects of pain from the person in pain. Pain is not a consistent marker of physiological or pathological processes (Klippel, 1997).

Kugelmann (2000) conducted a phenomenological analysis of 42 narratives of the milieus of pain investigating both the psychological as well as physical interpretation. He proposed that the narratives of psychological and physical pain have similar plots. They begin with a wounding, they are felt, they alter the existential world, they disable, and they isolate. Kugelmann argued that pain is the inability to act, because the 'it' that hurts is simultaneously 'me'. In chronic pain conditions like arthritis, pain straddles the mind/body distinction (Jackson, 1992) and should be studied as such.

Arthritis, in its many forms, is Australia's major cause of chronic pain and disability, and affects an estimated 16.5% of the population (Access Economics, 2001). Disability in arthritis is the result of the combination of three main factors: the arthritis itself, inactivity, and the aging process (March & Stenmark, 2001). Individuals and their illness behaviours can only be understood within the framework of past experiences, personality, family and cultural standards and current interpersonal reactions (Borkan, Reis, Hermoni & Biderman, 1995). Despite these variables, patients and health professionals alike see pain as the key determinant of health perception in people with arthritis (Kazis, Meenan & Anderson, 1983; Heiberg

& Kvien, 2002). Pain demands attention (Eccleston & Crombez, 1999), which in itself is potentially disabling.

OA and RA are chronic, progressive conditions that fall under the umbrella of arthritides, which collectively is a group of about 150 different non-curable diseases that affect joints, bones, connective tissue, organs and muscle to varying degrees. OA is considered to be the most prevalent activity limiting condition amongst older persons (Hampson, Glasgow, Zeiss, Bikovich, Foster, & Lines, 1993) and is classed as a degenerative arthritide, which occurs when there is repeated microtrauma to articular cartilage.

RA is a chronic inflammatory arthritis that is of unknown aetiology. In classifications according to pathophysiology, RA is identified as an inflammatory arthritide because it involves a prostaglandin-mediated inflammatory process, and thereby produces joints that are red, hot, swollen, painful, and dysfunctional (Ferrari, Cash, & Maddison, 1996). RA however, is not solely a joint disease; systemic manifestations such as fatigue, fever and weight loss may be present (Kochevar, Kaplan, & Weisman, 1997).

Although the symptoms experienced in both RA and OA include degrees of pain and stiffness (impairment) and reduced function (disability), arthritis is not simply a gradual deterioration the body. The consequences of chronic illness may be as far reaching as declines in an individual's self-concept or social relations. In 1982, Kaplan and Bush coined the phrase *health-related quality of life* (HRQOL) as an umbrella term including the concepts of perceived health status and subjective well-being. In 1990, Kaplan went further into this evolving concept and argued that behavioural outcomes are the most important consequence of the provision of health care. Information on HRQOL is particularly useful in evaluating health outcomes, as

collecting self-reports of HRQOL is the only direct way of obtaining a patient's perspective (Hawthorne, Buchbinder, & Defina, 2000).

Irrespective of what actually happens, or what others think is happening, people are influenced by their own perceptions (Payton & Nelson, 1996). It has been argued that HRQOL measures should include a subjective dimension based on the personal values and individual beliefs of the participants (Knebl, Shores, Gamber, Gray, & Herron, 1993). The World Health Organisation (WHO) Quality of Life Assessment Group, defined QOL as an "individual's perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards and concerns" (Kuyken, Orley, & Power, 1995). The patient's perspective on QOL is central in this definition and encompasses the personal evaluation of his or her physical health status and psychological and social functioning (Suurmeijer, Reuvek, & Aldenk, 2001).

Because there is no therapy that can clearly and consistently arrest the natural courses of RA or OA, individuals living with either of these long-term chronic conditions are challenged to take responsibility for their health care, in partnership with health professionals (Bongetti, 1999). People with arthritis learn to appreciate the limitations of conventional therapy and, as a consequence, many people with arthritis have turned to alternative medicine (eg. osteopathy, chiropractic, herbal remedies, massage therapy, yoga, acupuncture etc.). These approaches may be perceived as more congruent with their own values, beliefs, and philosophical orientations towards health and life (Astin, 1998). Marcus (2002) argued, perhaps somewhat cynically, that the exploration of alternatives to conventional therapy illustrates that human nature has the need for hope. Alternative treatments may also allow patients to self-manage their symptoms, empowering them, and sometimes

combating exaggerated fear of conventional medications, or satisfying the need to gain control over their pain (Marcus, 2002; Rao, Mihaliak, Kroenke, Bradley, Tierney, & Weingerger, 1999). There is a lack of evidence as to whether these alternative therapies, including some manual therapies, influence arthritis progression or symptoms; regardless, they continue to be widely used by people with arthritis (Lorig & Fries, 2000).

The efficacy and effectiveness of manual therapies for specific arthritic complaints is under-researched, and because of the physical contact component, these therapies do not fit well into the double blind clinical trial model of efficacy research (Cameron, 2002; Chambless & Hollon, 1998).

Joint mobilization, or articulatory technique, is a direct technique that applies a controlled force through the joint. The use of this technique by a skilled therapist involves the application of gentle and repetitive forces to the part of the body being treated so that they act against its restrictive barrier, with the intent of reducing the resistance or changing the position of that barrier and improving physiological motion to stretch contracted muscles, ligaments and capsules — and to a lesser extent move fluids (Patriquin & Jones, 2003). This technique is particularly useful where the application of slow, gentle, controlled movement is required, as is deemed the case with arthritis (Tucker, 1969). Joint mobilization is a technique that is used by many passive therapies (eg. osteopathy and physiotherapy) to help facilitate these effects. The process of degeneration is thought to be amplified with inactivity of the joint, so it is reasonable to hypothesize that passive joint movement by a skilled practitioner could provide maintenance of functional mobility and contribute to a more independent and improved QOL (Knebl et al., 2002). Restriction in usual activity is seen as prima facie evidence of deviation from well-being (Kaplan, 1990).

In two studies completed by Cameron, Andersen, and Speed (2004a, 2004b), people with osteoarthritis or rheumatoid arthritis underwent 10-week trials of manual therapy (either massage or joint mobilisation). In the trial for people with OA, 19 participants completed the trial from the original cohort of 20. In the trial for people with RA, 11 participants completed the trial from the original cohort of 14.

Participants in these trials were volunteers, and were free to withdraw from the trials at any time. Three of the four non-completers reported worsening pain as rationale for withdrawal. Only one non-completer provided follow-up data via returned questionnaires. Most participants completing the trials reported small improvements in health-related quality of life (HRQOL) over the duration of the trials. These improvements were not associated with increased intake of pain medication or increased social support. A small number of participants reported considerably larger improvements in HRQOL.

Following these studies, a knowledge deficit existed because Cameron et al. (2004a, 2004b) were unable to identify why some participants responded very well to manual therapies, and some participants responded very poorly, while most participants experienced modest gains. This study is an attempt to determine if those participants who responded very well, or very poorly, to manual therapies are able to shed any light on why these discrepancies occurred.

The aims of this study require the collection of descriptive and qualitative data rather than quantitative data, and so a qualitative research methodology was most suitable.

Grbich (1999) cited the interview as the most commonly applied research method and the most appropriate means of collecting information on events or phenomena which are not readily observed.

METHOD

Background

Four participants from a series of previous studies by Cameron, Andersen, and Speed (2004a, 2004b) were invited to participate in this study in order that their perceptions of success or failure of the previous studies might be explored. In Cameron et al.'s (2004a, 2004b) study, participants were randomised to groups to receive either a manual therapy (joint mobilization or massage), warm water exercise, or no adjunctive intervention (usual care) as weekly interventions for 10 weeks. All participants continued with ordinary care, and periodically completed a battery of HRQOL questionnaires. In the second of Cameron et al.'s studies, 3 participants withdrew citing worsening pain, and 1 participant did not return any questionnaires. Each of these participants had rheumatoid arthritis. In two later studies by Cameron et al., participants receiving manual therapy interventions reported consistent improvements in HRQOL over the course of the trials. These improvements were demonstrated by large to very large effect sizes associated with group allocation (i.e., eta squared). Participants in the later Cameron et al. studies had OA rather than RA. The purpose of this study was to explore participants' perceptions of success or failure of manual therapy as a HRQOL intervention in arthritis. In particular, we were interested to determine whether perceptions of success or failure were linked to either: a) disease profile, or b) type of manual therapy.

Participants

Three participants: 2 females who had RA and OA and 1 male who had OA, agreed to be interviewed, and returned signed, completed consent forms as evidence of this agreement. Of the three participants, only one completed a Cameron et al. (2004b) trial (i.e., responder: one who demonstrated benefit from the intervention), and the other two were classed as non-responders.

Measures

The interview was semi-structured (see Appendix A). The questions were guidelines for the interviewer to direct the line of questioning, but were not asked rote. The interview was a form of discourse, constructed jointly by the interviewer and respondent (Mishler, 1986).

Procedures

Both this study and the previous studies by Cameron et al. (2004a, 2004b) were approved by the Victoria University Ethics Committee. Upon ethics approval, responders and non-responders from the Cameron et al. studies were invited in a telephone conversation with Melainie Cameron to participate in this follow-up study. People who expressed a desire to participate in this study were sent a formal invitation, detailed information about the study, and a consent form. When completed, signed consent forms were received by the researchers, mutually agreeable times were scheduled for interviews. A maximum of one hour was allocated for each interview.

The decision to conduct the interview by telephone was made as a control measure for those participants who experienced worsening HRQOL during the original trials. This was undertaken to pre-empt the possibility of their responses being colored by returning to the environment in which the interventions took place.

The participants were telephoned ahead of time to confirm their intention to participate and that the interview time was suitable. Each participant was interviewed by an osteopathic student who had been involved in the original studies, but had not provided manual therapy interventions for that participant. With participants' consent, all interviews were audiotaped.

The phone interviews were transcribed and analysed using content analysis for identification of themes and sub-themes. Transcript analyses identified major themes by identifying and naming each idea or event (both identified as concepts) and then grouping concepts that related to the same idea into categories. If common themes were identified across interviews, data were pooled.

Each participant was offered the opportunity to view and verify their interview transcript before any data were analysed. Participants were informed that they were free to decline to answer any question, to terminate their interview, or withdraw from the study if they so choose. For a period of two weeks after conducting the interviews, participants could withdraw any statement from their transcripts by notifying the researchers.

RESULTS

Main themes emerging from the interviews have been grouped into two key sections. The first section, Joint Mobilization and Health-Related Quality of Life covers the themes arising from discussion of the original studies and joint mobilization as a specific intervention. The second section, Health Beliefs, covers themes associated with the individual participants, their attitudes, personalities, and thoughts about healthcare.

Joint Mobilization and Health-Related Quality of Life

Effects of study design on treatment outcome

All three of the participants reported that the way in which the original studies were conducted was satisfactory and had no negative impact on their treatment outcomes. Participants described the study atmosphere as *professional*, *relaxed*, and *warm*. Participants also reported being able to combine other enjoyable activities, such as going out for coffee, with the study appointments.

A-It was fine, not a problem at all, quite relaxed.

B– I think it was run very professionally and was very warm towards the client...you knew they knew what they were doing and you quite enjoyed the visits really.

C – It was so easy for us to come on the train and Flinders Street right across the road. I was quite happy...we would go for coffee at Gloria Jean's.

Time lapse between initial treatment and this study

It was suggested by two of the three participants that the length of time between treatment and questioning made it difficult to recall the circumstances of their treatment experience.

A – My memory. I knew that we were going away but it could have been... What time of year? [thinking to self] Do you have the date?.... I hope my answers were not too vague. It happened 12 months ago you seem to forget.

B – $Oh...now\ I$ have to think back now [silence].

Data collection for the Cameron et al. (2004a, 2004b) studies lasted one year. This follow up study commenced when data collection from the original studies was complete. For participants who withdrew from the first of Cameron et al.'s studies, almost 12 months elapsed between their two involvements with this series of investigations.

Pre-treatment expectations

Participants described their motivation to enter the study in terms of inquisitiveness.

B-To see what was actually done and I was very interested in the end result.

C-I wanted to discover what the treatment could do...

Participants also had hopes of what the treatment might achieve, particularly reduced stiffness and improved mobility.

A – I thought that I would rejuvenate, like... ah.. with arthritis '''like if you don't do things, it stiffens... I thought a bit of manipulation sort of thing to a point might help, that was my basic expectation... Well I suppose I thought it was going to help the arthritis, more physical... I don't think I had emotional expectations. I knew they would not come up with a cure, but just something that would help.

Reasons for withdrawal from treatment

Two of the three participants were non-responders, that is, they had withdrawn from the Cameron et al. (2004a, 2004b) studies. Participants who withdrew from these studies were not required to provide explanations. Regardless, both these participants explained their withdrawal from the original studies at the time as being due to increases in their pain. When asked to reflect upon their withdrawal as a part of this study, both participants provided alternative explanations.

A-I was going away and it wasn't really doing me good as well...as the time went on I could feel it more. You see my shoulders gradually got worse. The actual manipulation is a bit too invasive for me.

C-It was impossible to carry on... it wasn't because I wasn't happy with it or anything like that, the surgeon said to stop all manipulation.

Effects of communication during treatment

One of the three participants did not feel communication ultimately impacted on study outcome.

B – Added to the enjoyment, but I would have to say that it did not make much difference to the end result.

The other two participants really looked forward to the conversation shared in the treatment room during the 40-minute intervention. Participant C expressed these feelings beautifully.

C – Conversation is what I enjoyed...half the time I told my life story... but I have a great life story [laughs].

Perceived impact of treatment on HRQOL

Only participant B completed the original study. This participant perceived the benefits of the intervention as increased activity and physical function.

B – I did have improved range at the end of the term. You got improved health related quality of life because you had improved movement ... I think that the extra insight gave you more insight to motivate perhaps to work on the areas to get them going better... you were gaining a knowledge... you were working on the situation... I think it [mobilization] was an added that helped the stiff joints, I think there was improvement with the treatments.

This participant was ambivalent about the effect of joint mobilization on pain.

Initially, she was uncertain about the longevity of the treatment effects, but on reflection, reported that some improvements in joint range and reduced stiffness occurred gradually. She may not have noticed these improvements during the study, but at the end of the study observed that she was more mobile than she had been at the beginning.

B – It did ease the pain... but I do not know if it really did... You think it does temporarily but it is very hard to judge. Because it is only short lived relief... You know I say it only lasted for the week but I think over the period the movement in some of the joints did improve so I contradicted myself. Because I did have improved range at the end of the term. In the certain joints that were more restricted so therefore I did have improvement yet I have not noticed it through it.

Health beliefs

Health locus of control and openness to new ideas

Participants demonstrated strong internal health loci of control. They intentionally and deliberately pursued treatment options. They volunteered for clinical trials. Some participants were open to alternative therapies, and new, untested, or radical interventions. Other participants preferred orthodox medical interventions, arguing that they were well tested.

A – I went to the Alfred [Hospital]. I did that for three or four months I suppose, but I had to withdraw from that too... You have to try things to find out things don't you... With arthritis you got to be open to anything. I have to keep going.

 $\emph{\textbf{B}}-\emph{\textbf{I}}$ tend to go for the straight classical treatment...they are tried and tested and you know what you can expect and you know what to watch for.

Emotional contribution to pain

All participants reported increased pain when they were under increased stress. For example, participants C's partner had just been diagnosed with cancer just prior to the interview.

C - ... not at the time, but there is at the moment. It is affecting our lives at this moment as well ...

A-Pain is worse when I get myself tensed up.

Costs versus benefits of treatment

Participants were questioned if they would seek out any form of manual therapy in private practice. All participants reported that the cost of care prevented them seeking manual therapy privately. Even participants who withdrew from the original studies reported that they would consider using manual therapies again, if the cost were not prohibitive.

A-If it wasn't for the cost yes you probably would, because your joints are better for being moved. It is a cost and effect...it would not be cost effective for me at this stage as I still have the movement.

B-...probably the cost. If it wasn't for the money, yes I would.

C – They are really expensive and they are not on the health plan. The main thing stopping you from getting treatment yourself is the money.

Compliance

A requirement of the Cameron et al. (2004a, 2004b) studies was that participants were to continue taking medication and to continue all activities that they had been involved in before entering the trial. In these interviews it became apparent that not all participants had adhered to this directive. Participant A indicated that she had not maintained her usual levels of physical activity during the trial.

 $A-Maybe\ I\ did\ not\ go\ quite\ as\ much\ [during\ the\ study].$

B-Yes I had not changed anything. I was very active before I went into the study.

Continuity of care affects treatment

As far as possible, participants received treatment from the same studentpractitioner throughout the original studies. In the course of three 10-week trials, it was necessary that some participants receive treatment from more than one person.

A-Yes, yes, I had the same person all the time.

B-I had ----- a couple of times, but other than that I had the same student.

Although all student-practitioners in the original studies were trained, and received written instructions to follow, participants noted differences between practitioners.

C – Most of the time it was the same one [practitioner], but every now and then it was a different one...there was a difference...it seemed more than anything else that she was sure that what she was doing was okay, but the others were always asking if you are alright.

C – We had a different lass at that particular time... I said I was told not to have any other manipulation on that right leg, so leave it alone. It was just one of the accidental things, the girl picked it up and started moving it, and I said 'Hang on, don't touch that leg.'

Participant education

Participants reported that there were educative outcomes associated with the original studies. They learned more about arthritis, and how it affected them as individuals. They used this knowledge to motivate themselves to maintain interventions.

B-I think it made me more aware of where to work on my problems...Gave you more insight to motivate... perhaps to work on the areas to get them going better...mobilization helps lubrication of the joint and helps keep the flexibility of it.

DISCUSSION

The aim of this study was to determine why the participants deemed joint mobilization a success or a failure. Existing research reports that pain is a HRQOL domain of great importance for people with arthritis. When participants withdrew from the original studies, they cited worsening pain as their reason for doing so.

Heiberg and Kvien (2002) assessed HRQOL in people with RA using the Medical Outcomes Study 36-Item health Survey (SF-36), the Arthritis Impact Measurement Scales Version 2 (AIMS2), and a visual analogue scale for pain (VAS). The AIMS2 includes a section for participants to nominate three priorities for future health improvement. Heiberg and Kvien found that pain was the domain of greatest priority in people with RA. They did not report the pain scores of their participants, but they did report a comparison between participants who cited pain as a priority area for health improvement and those who did not. These two groups differed significantly on each of the three pain scales completed (i.e., as well as the VAS, the SF-36 and AIMS2 include pain scales), but did not differ significantly on any measures of physical function (i.e., disability). It is hardly surprising that if you experience a lot of pain, then in your priorities for health improvement, reduction of pain rates highly.

Functional status is as important as pain

Farr, White, and Maged (2000) argued that the most important index to the benefits of health care is: "Does the patient believe the therapy or investment has been beneficial to them?" This follow-up study was an attempt to answer this question by asking participants about their actual impressions regarding a therapeutic intervention (joint mobilization). In this type of enquiry some questioning of the status quo is permitted. Researchers seek participants' opinions and beliefs. These results may contradict or confirm the researchers' already formed beliefs (Hasluck, 1975). I expected, consistent with the work of Heiberg and Kvien (2002), that pain would be cited ad nauseum as the explanation for either success or failure of the Cameron et al. (2004a, 2004b) studies. That is, if their pain decreased, participants would report the study as a success, and if their pain worsened, participants would report the study a dismal failure, and probably, withdraw from it.

When interviewed, participants in this study appeared to place much greater emphasis on functional outcomes of the treatment rather than pain. They withdrew from the study if there were complications, or flare ups in the diseases during the trial, but deemed the intervention a success if their functional capacities improved over time. For example, Participant A had previously experienced improvements in function from her exercise program. She was looking for a similar benefit from manual therapy. Unfortunately she also experienced increased pain, and withdrew from the Cameron et al. (2004a) study.

A – I have to keep up some sort of exercise program otherwise I can feel myself stiffening up...and I thought I would rejuvenate..like ah..with arthritis like if you don't do things it stiffens...I thought a little bit of manipulation sort of thing to a point might help that was my basic expectation I suppose.

Clearly pain and physical function are both of equal importance to this person, however, it appears that if she could obtain improvements in function, she would tolerate pain. Worsening pain prompted her withdrawal from the study. Stable pain, concurrent with functional improvements, would likely have been adequate for this participant to remain in the study until its conclusion.

Hawley and Wolfe (1991) researched seven different rheumatic disorders, including OA and RA. In a study involving 1522 patients, they found that pain and functional disability are among the most important outcomes of rheumatic disease, and that the relationships between pain and disability are complex, and variable among disease profiles. For example, they found that the ratio of pain to disability scores was nearer 1 in people with RA than in people with OA. The same ratio was smaller in people with OA of the hands than those with OA of the knees. These results mean that although pain and disability are present in both disease states, for

people with RA, disability approximates pain in both severity and importance. In people with OA of the knees, however, pain is of considerably less severity or importance than disability.

The interviewees in this study challenged the one-eyed view that pain is the all-important HRQOL domain for people with arthritis. Rather, they suggested that it is necessary to take a broader view of health improvement. Kaplan (1990) argued that behaviour change is the outcome that matters most in health care delivery. Although Sechrest, McKnight, and McKnight (1996) referred to outcome measures in psychotherapy, their comment applies equally to outcomes in most types of clinical interventions, including physical and manual therapies:

Actual change in behavior or functioning is critical for assessing treatment outcome, rather than simply inferring change from a metric of uncertain meaning. Effective treatment ought to signify that as a result of undergoing a particular procedure, a person is better in demonstrable ways (p. 1065).

Kaplan (1994) later embellished this argument with an example from the comic strip Ziggy, in which Ziggy climbs a mountain to ask a guru the meaning of life. The Guru responds that "The meaning of life is doin' stuff." When Ziggy queries this response, he is told "As opposed to death, which is NOT doin' stuff." "Doin' stuff" is behaviour and functioning, and unless treatments influence these variables, then their usefulness is questionable.

Changes in two general categories of outcomes can be expected from health care interventions: functional status and well-being (Sechrest et al., 1996). If people can do more (e.g., physical function), or feel better (e.g., perceive less pain), after an intervention, then their HRQOL may be said to have improved following the intervention.

RA and OA are prevalent, have no known cause or cure, are characterised by chronic pain and have a variable disease course, and often adversely affect functional status (Rao et al, 1999). Have you listed up to 6 authors at first use? I am not sure. Please check. OA is considered to be the most prevalent activity-limiting condition amongst older persons (Hampson, Glasgow, Zeiss, Bikovich, Foster, & Lines, 1993). Interestingly, in the study conducted by Heiburg and Kvein (2002), they noted a distribution of preference for improvement for younger patients to be in areas of pain, work and mental condition, and in the older or elderly, the emphasis was on physical functioning. The average age of the interviewees in my study was 67 years, and they too put the emphasis on functional gain.

A - there is a lot of things that I cannot do and I have gotten a lot worse in the last couple of years I suppose.

Clearly, the components of HRQOL that matter most may differ between people. Age may provide some explanation, and it is likely there are other explanatory variables. I suggest that clinical meaning should be attributed to improvements in the domains that matter to the individual. A one percent improvement (small effect size) in a variable known to be important to a client may be more meaningful than a large improvement in a less salient domain. Participant A expressed her frustration at functional limitations.

A - My emotional part I am feeling a lot better...but my physical part my shoulder and that are not good. Even talking on the phone now it is not good...I rest it on the arm the couch but you know well I cannot walk as far...I can't do a lot of housework. I can't my restrictions are with my shoulders...like I can't pull things...like even making the bed is hard job...vacuuming washing the floor...I can't hang up the clothes...a lot of restrictions I have got at the moment and I just feel that ...and

walking as I said. I can walk but I can only go for short distance...like around the block, that is the extent of it. I am limited in a lot of the things that I do...I rely a lot on my husband, to comb the hair, wash the hair, and things like that are very restricting for me.

I recommend that healthcare practitioners take the time to discuss health status priorities with their clients, and set individual priorities for improvement at the commencement of intervention.

Participants were very reluctant to report the original studies as failures, even if they had experienced worsening symptoms, or withdrawn from the study. Participant A tried to brush aside her withdrawal with an explanation of going on a holiday. Deeper probing revealed that this participant experienced an arthritis flare severe enough to have her admitted to hospital, and she withdrew from the original study on the recommendation of her rheumatologist. The participant was determined to say nothing negative about Cameron or her co-workers, and reported being highly satisfied with the professionalism of the study. She used descriptors such as *warm* and *friendly* and *nice* when speaking about the researchers, and tended to blame herself or the arthritis for her worsening symptoms.

The relationship between physical function and satisfaction, or other psychosocial variables, is complex. Pincus, Summey, Soraci, Wallston, and Hummon (1983) demonstrated that satisfaction levels vary considerably among people with comparable physical health status. Meenan, Mason, Anderson, Guccione, and Kazis (1992) confirmed that in groups of people with OA or RA assessed using the AIMS2, satisfaction and function are only moderately correlated. It is possible that, as she reported, Participant A was satisfied with the original studies, even though she experienced worsening pain and considerably functional decline.

Health Beliefs

Covic, Adamson and Hough (2000) looked at the predictors of pain in people with RA, and found that the only significant predictors of pain were physical disability and passive coping strategies. Passive coping strategies were considered to include praying, giving up social activities, and relying on health professionals for pain relief. Covic et al. pointed out that these passive coping strategies typify the lack of control patients feel over this condition. This finding highlights that people with RA have to live with some pain, but their health beliefs and the behaviours arising from these beliefs, may contribute to their development of pain.

The participants in this study demonstrated a very high level of self-efficacy - the belief that one has the ability to control or cope with the symptoms of the disease (Lorig & Fries, 2000). Their quest to try new things, including alternative therapies, gave the impression that this was a sample of highly driven people, and as such may not reflect the typical person with arthritis. We did not explore the factors that motivate people to routinely volunteer to participate in clinical research, however, it is likely that such individuals may be more self-motivated than the general population, have strong internal loci of control, and high self-efficacy. It should be remembered that these aspects of the individuals, reflected in the interviews, are traits of the participants, not of the study.

Williams and Calnan (1994) found that the consulting relationship in allopathic medicine appears to be one that is characterised by a dominant and active doctor and a passive, dependent patient, which leads to the dominance of the doctor's perspective over that of the patient. This dominance is perpetuated by the lack of information which doctors give patients; which is tied to issues of professional power, status and authority. Temby and Cooper (1996) in writing for general medical practitioners,

cautioned that in looking to confirm a label (e.g., arthritis equals pain management) practitioners may miss seeing the person. Lack of a patient-centered approach in assessing need for care may lead to ignorance of symptoms and issues prioritised by individuals (Kaplan, 1990; Tallon, Chard, & Dieppe, 2000).

Alternative therapies are available through the public health system rarely, in limited quantities, and only upon referral from a general medical practitioner (GP; Australian Government, 2004). Allopathic and orthodox practitioners differ in the amount of time spent with the patient. This situation has arisen largely as a product of the public Medicare health system that pays for general practitioner consultations, but at a rate that is less than general practitioners are satisfied to earn. GPs may choose to either reduce consultation times, or change additional private fees. Alternative medicine practitioners on the other hand, charge private fees for consultations, and have the freedom of longer consulting times, but a smaller, able-to-pay, client base.

It is clear from the findings in this study that the cost of alternative therapies is an impediment to seeking out alternative forms of treatment, in this case, joint mobilization. Our findings are consistent with the argument by Kaplan (1990), that treatments would be favoured if they produced the most benefit at the lowest cost.

A - I am interested and if they work all the better, and to start with they save you a bit of money.

Patients with limited budgets may favour one course of care (alternative versus traditional) based on their perception of the relative merits of these treatments and their cost. Based on their beliefs in the relative value of alternative versus traditional therapy for OA, they may feel compelled to substitute care from one modality for another (Ramsey, Spencer, Topolski, Belsz, & Patrick, 2001)

Because alternative medicine practitioners are in a position where they have greater time to spend with their patients, they also have more time to create a therapeutic bond and thus possibly have a greater influence on patients' HROOL. There is more time to talk and chat and more time to be genuinely empathetic. In counseling psychology, "the quality of the counseling relationship has proved to be the most significant factor in facilitating treatment adherence and positive counseling outcomes." (Petitpas, Giges, & Danish, 1999, p. 344). The working alliance is the collaborative relationship between the client and the therapist, working together to improve the psychological functioning (health) of the client. The quality of the working alliance influences treatment outcomes, partly because a strong working alliance is an important factor in a client persisting with treatment through a plateau or setback. In general terms, as people age they also decrease their social interactions. Participants in this study reported that they looked forward to appointments, not just for the effects of the actual treatment, but the social interaction. How much the therapeutic alliance had to play in the perceived effectiveness of the treatment is not quantifiable but needs to be appreciated in the context of the study results.

Perceptions of practitioner competence. In the original study there was some variability in the student practitioners performing the joint mobilization. Although the participants were very positive about there experience, it is an aspect that could have affected the quantitative findings. There was a difference noted between the skill of the professional osteopath and the student osteopath in this study. The main point of difference was not that the student was any less skilled at performing the technique (lacking years of clinical experience), but more that they were perceived as less confident in their conduct. This variation in perception could have subconsciously altered the patients' experience of the treatment. Clients' perceptions of practitioners'

skills, confidence, and the development of the working alliance between the therapist and the client were not main themes of the interviews, but are worthy of further exploration in future research.

Possible explanations of withdrawal from the original studies

It is a standard proviso for the ethical conduct of the study that participants are free to withdraw at any time (Victoria University, n.d.a., n.d.b). When participants withdrew from the original studies, they reported that they had experienced worsening symptoms, particularly increased pain. Participants were not required to give any explanation for withdrawal from the study. That they chose to do so is useful because it highlights two important aspects of living with arthritis: (a) the priority given to pain, and (b) the fluctuating symptoms of the disease.

In designing their studies, Cameron et al. (2004a, 2004b) may not have fully accounted for the episodic nature of arthritic disease, particularly RA. For example, they may have attributed too much weight to scientific literature reporting that RA is a relatively stable disease over short to medium periods of time (Meenan, Kazis, & Anderson, 1988; Roche, Klestov, & Heim, 2003), and placed inadequate weight on lay literature advising people with RA to abstain from exercise or manual therapies during disease flares (Lam & Horstman, 2002). Such lay literature is developed out of the experience of clinicians and people with arthritis, and is a "real world" account of what people with RA feel able and confident to do during disease peaks. Meenan et al. (1988) used the Arthritis Impact Measurement Scales (AIMS) to assess the stability of health status in people with RA over 5 years and reported no "clinically important deteriorations" on any subscales (p. 1484). It is worth noting that 111 people of the original cohort of 410 were lost to follow-up. Any clinically important deteriorations of RA in the people who withdrew from Meenan et al.'s study could

not be determined. In those people completing the study, brief fluctuations in health status, such as flares, may have been overlooked because data were collected at the beginning and end of the five-year period only. Because the sample size was large (n = 299) variance in health status scores due to a few participants having flares at either data collection point is likely to have been: (a) small, and (b) approximately equal in both data sets. On the basis of the data gathered, it was reasonable for Meenan et al. (1988) to conclude that RA may be "more stable than previously thought," but that picture of stability over time belies the clinical flux experienced by people with RA (p. 1484).

In contrast, Lam and Horstman (2002), in *Overcoming Arthritis*, a book for people with arthritides, wrote that:

It can be frustrating and depressing to cope with RA because it is so unpredictable and so painful. Symptoms can come and go without warning and vary from person to person. ... Most people suffer through cycles of flares and remissions. (p. 18).

Lam and Horstman (2002) also advised that massage, and by implication, other manual therapies, should be avoided during disease flares: "hot, swollen joints should not be massaged" (p. 66). There is no scientific evidence, but common wisdom, that joint mobilisation aggravates symptoms during RA flares. Participants who withdrew from this study at times of increased pain acted in keeping with common sense advice.

Limitations of this study and recommendations for future research

Because only 3 individuals were interviewed in this study it can be fairly argued that the sample is not strong enough to draw any conclusions, but it does serve

as a template for further enquiry and the themes that evolved are consistent with findings found in large-scale research.

The most important aspect of qualitative data collection is the ability to create a rapport with the interviewee. This was made difficult in this study in the absence of face-to-face contact, as the collection of data for this study was gathered through a semi-structured telephone interview. Difficulty was encountered keeping the dialogue flowing and use of the phone to gather data highlighted the inability to access nonverbal cues and body language. Although the data collected were valuable, the quality may have been compromised due to the approach used to gather it.

Admittedly, this was my first qualitative study and I did find that the quality and general flow of my interviews improved throughout the course of the interviews. As a result, the quality of information extracted was far better by the final interview and the amount of pregnant pauses that initially threw my train of thought also declined as I learned how to overcome them.

Another issue that was encountered in the questioning was asking if the participants felt they received benefit from the study. Several issues are subsumed in such a question. In their qualitative study looking at the implications of the question *Are you better?* Beaton, Tarasuk, Katz, Wright, and Bombardier (2001) found that the interpretation of this question varied widely. Questions about benefit from treatment are important because they give clinical practitioners information about effect of treatment and guide clinical decisions regarding the next step (Feinstein, 1996). The construction of the question *Are you better?* assumes a resolution of the disorder. Resolution takes three different forms; change of magnitude; symptom relief; and being better able to cope with the condition (e.g., pain) even though it continues. This final situation is applicable to people with arthritis who may keep symptoms under

control with use of medication, exercise, therapeutic interventions, and also modify behaviour (using devices to assist in movement and tasks and limiting aggravating activities). Although the question *Are you better?* was not posed as such in this study, it is possible that my questions regarding treatment effects and improvements may have carried several possible interpretations.

An unfortunate hurdle in the interview period was that quite a period of time had lapsed between the completion and/withdrawal from the study and the time of the interview. Each of the participants found it difficult to recall with great certainty the details of how they felt about the intervention being used and how they felt at the time of the trial. To maximize recall in qualitative research it would have been worthwhile to try and keep the interview and the intervention closely linked, however, this enquiry was not planned when the original studies were commenced. Cameron and co-workers (2004a, 2004b) did not anticipate that participants would experience HRQOL declines enough to prompt withdrawal from the study, and thus, had not intended to investigate this issue. This oversight emphasizes that although qualitative and quantitative enquiry are have different purposes, they may sensibly be used together to explore the many facets of a complex issue (Grbich, 1999). Cameron et al. would have been well advised to plan a qualitative investigation as a component of their original studies.

The episodic nature of rheumatoid arthritis was a marked problem in one of the original studies by Cameron et al. (2004a). The possibility of disease flares is a difficult variable to control for in a set research time frame. Disease severity is important because RA is progressive disease with serious physiological sequelae that lead to increased disability. The cause of the disability at one stage of disease (pain and fatigue), may be different from the cause of disability at a later stage (deformity)

(Kochevar, Kaplan, & Weisman, 1997). These considerations, coupled with, the high rates of co-morbid diseases amongst older persons makes disease management more difficult (Verbrugge, Lepkowski, & Konkol, 1991), and this difficulty carries over into any clinical research investigation.

CONCLUSION

This article does not dispute that individuals who live day to day with OA or RA are in pain. Rather, it makes the point that at some level these individuals put a high priority on their functional capacity. Being able to undertake daily tasks and maintain an independent life were common themes that emerged in all the interviews. It is a common perception amongst health care practitioners, that if one limits the pain one will increase function, and to some degree that is true. By focusing on the pain there is a risk of developing a hyperviligence by the patients, to particular body sensations, which may result in a psychological sensitisation that then amplifies the complaint (Eriksen & Ursin, 2002).

Cameron et al. (2004a, 2004b) concluded that their quantitative study was a failure. However, the findings of this small-scale qualitative enquiry supports their idea that joint mobilization can aid in bringing about improved QOL, particularly function. This article is a gentle reminder that presumption of a patient's wants can stifle therapeutic progress. All health care practitioners (allopathic or alternative) would benefit from questioning their patients about their individual experience of a disease process and expectations of treatment. No one has the right to presume the needs of anyone.

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Appendix A:

Interview Template

Semi-structured interview A: Participants who withdrew from previous trials

Use questions as starting point for discussion. Allow participant to speak freely, voicing their opinions, feelings, and thoughts. Bring the discussion back to the topic if wandering, but do not limit discussion with closed-ended questions.

You withdrew from Melainie Cameron's arthritis study. I know that your participation in the study was voluntary, and you were free to withdraw from it if you wished. I would appreciate it if you could explain for me what motivated you to withdraw from the study at that time.

If unclear, prompt with:

What were your reasons for withdrawing from the study?

If the participant identifies worsening pain / function / activity levels / HRQOL as reason for withdrawal, ask:

Can you identify when your pain / function / activity levels / HRQOL first began to worsen?

Can you identify anything else you have tried as treatment for your arthritis that led to your pain / function / activity levels / HRQOL worsening?

Do you consider that your pain / function / activity levels / HRQOL declined in response to the manual therapy?

Do you consider that your pain / function / activity levels / HRQOL declined in response to other factors in your life? (eg: an unexplained flare up of arthritis, emotional or physical stress outside of the trials).

If the participant identifies personal, logistical, or social issues as reason for withdrawal, ask:

Thank you for explaining those reasons to me. What would it take for you to be prepared to take part in a trial of manual therapy for arthritis again?

What would it take for you to be prepared to try out a form of manual therapy (eg: massage, osteopathy) in a private consultation?

Semi-structured interview B: Participants who responded very well in previous trials

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	Use questions as starting point for discussion. Allow participant to speak freely, voicing their opinions, feelings, and thoughts. Bring the discussion back to the topic if wandering, but do not limit discussion with closed-ended questions.
	You took part in Melainie Cameron's arthritis study. Could you explain for me how the manual therapy program benefited you personally?
]	If unclear, prompt with:
	What did you find good, enjoyable, useful, or therapeutic in the study?
	If the participant identifies improving pain / function / activity levels / HRQOL as reason for success, ask:
]	Can you identify when your pain / function / activity levels / HRQOL first began to improve?
	Can you identify anything else you have tried as treatment for your arthritis that led to your pain / function / activity levels / HRQOL improving?
	Do you consider that your pain / function / activity levels / HRQOL improved in response to the manual therapy?
]	Do you consider that your pain / function / activity levels / HRQOL improved in response to other factors in your life? (eg: an unexplained decline in arthritic symptoms, a new medication not disclosed to the researchers).
] .	If the participant identifies personal, logistical, or social issues as reason for success, ask:
	Thank you for explaining those reasons to me. What would you like to change or improve if you were to take part in a trial of manual therapy for arthritis again?
]	Would you be prepared to use a form of manual therapy (eg: massage, osteopathy) in a private consultation as part of your arthritis care?
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