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Title: To examine the experiences of individuals with arthritis who participated in an Occupational Therapy led Vocational Rehabilitation program

Abstract

Purpose: To examine the experiences of individuals with arthritis who participated in an Occupational Therapy led Vocational Rehabilitation (VR) program in order to assist them to remain in or return to work/education.

Method: Five participants who took part in the Working with Arthritis (WWA) VR program were interviewed using semi-structured qualitative interviews. The interviews aimed to gain an insight into the participant’s experiences of the intervention and identify the aspects that they found most beneficial. Thematic analysis using an inductive approach was used for data analysis. Interviews were transcribed, data was analysed using Nvivo 8 software, and information was coded and developed into themes.

Results: Participants positively evaluated their experience of taking part in the program. Five themes emerged from the data. These were (1) Experience of the therapeutic relationship with Occupational Therapist, (2) Positive experience of completing therapy in the home and receiving an individualised service, (3) Learning about their condition, self-management and services, (4) Experience/ participation was influenced by low expectations of return to work, (5) Occupational and other outcomes of participation in the programme.

Conclusion: Participant’s experiences of the WWA program were positively evaluated. The therapeutic relationship with the therapist, the implementation of therapy in the home and the experience of learning self-management were particularly valued by the participants. Vocational outcomes of the study were limited, however many other occupational outcomes were reported including; improved time use, occupational participation and increased engagement in and awareness of services. This information could be used to inform further research in the development of interventions.
Introduction
Arthritis is a common chronic condition which causes pain and progressive disability amongst millions of individuals globally (Barlow et al 2001). The pattern, severity and location of the symptoms can vary depending on the type of arthritis, but the suffering is frequently pervasive and detrimental (Barlow et al 2001; Andersen et al 2014). Arthritis is one of many musculoskeletal disorders (MSD) and is suggested to be the single biggest cause of disability in Ireland which affects around 915,000 people (Crockatt et al 2009; Arthritis Ireland 2015). MSD’s have a significant impact on an individual’s ability to work and are the most commonly reported cause of work related ill health in Ireland (Bevan et al 2009). 20-30% of arthritis patients becoming permanently work disabled within the first 2-3 years of the disease (Zirkzee et al 2008; Tamborenea et al 2015).

Vocational Rehabilitation (VR) has been identified across the literature as being a successful enabler to assist people with MSD’s in the process of maintaining or returning to work/education (Waddell et al 2008). Previous research has predominately focused on the outcomes of VR. However, there is a lack of research exploring people’s experiences of the VR interventions. Therefore, this study aims to explore the experiences of individuals with arthritis who participated in an Occupational Therapy led VR program.

Literature Review
Work is a meaningful occupation for many people, providing economic, personal and social benefits (Waddell and Burton 2006). To work in paid employment is to become part of society (Barenes and Holmes 2007). Work is the route to participation, social inclusion, good health, well-being and engagement in occupation that adds richness to people’s lives (COT 2008).

Vocation rehabilitation is an effective enabler in assisting individuals with MSD’s to overcome the barriers they face when accessing, remaining or returning to work/education (Waddell et al 2008; Kvam et al 2013). People’s experiences of VR in arthritis have not been well documented in the literature to date. However, a number of positive experiences of VR have been reported by people with other chronic conditions. In a small scale qualitative study, of 19 participants with multiple sclerosis, Jellie et al (2014) reported that VR interventions led to improved understanding of their symptoms and management in the workplace, reduced anxiety and increased confidence levels to advocate for themselves in the workplace.
Similarly, in a blended-method study investigating the impact of VR on occupational disability including participants (n=150), identified the establishment of good working relationships and increased understanding about self-management post VR interventions (Young 2010).

Occupational Therapists are experts in human occupation and purposeful activity with occupation being core of Occupational Therapy practice (COT 2008). Therefore, VR coincides with the primary aim of Occupational therapy to enable people to participate in the activities of everyday life (Wilcock 2006). A small number of studies investigating Occupational Therapy and VR have reported outcomes such as; improved ability to work, increased returning to work rate, employer education and adapting the work environment (Hammond 2008; Lambeek et al 2010; Desiron et al 2011). While the majority of studies highlight the positive outcomes for the use of Occupational Therapy in work related interventions, specific therapeutic interventions have not been clearly identified, therefore leaving the role of Occupational Therapy in VR underestimated (Desiron et al 2011). The importance of supporting individuals to engage in work with MSD on both an economic and personal level is clear. VR has many potential benefits, however the lack of evidence based practice surrounding individual’s experiences of these programs weakens it rationale for their use. Therefore, following consideration of the literature, this study aims to describe the participant’s experience of taking part in an Occupational Therapy led, VR program for people with arthritis.

**Methods**

**Study design:**

This study was part of a large scale study, where data were collected from between the years 2013-2015 on the WWA program, a 4-6 week Occupational Therapy led VR intervention that aimed to overcome the barriers that people face when returning to, remaining in or accessing work. The smaller scale study reported here used a qualitative research design to focus on exploring life experiences of individuals in their social context (Bryman 2008; Creswell 2009). The researcher was guided by the Interpretivist paradigm (Merriam 2002), informed by a phenomenological perspective which aims to provide a rich account of lived experiences (Braun & Clarke 2013).
Participants
Inclusion criteria for the WWA study included: male and female individuals between 18-65 years, eligibility for disability/illness payments, a diagnosis of MSD and residence in the Border, Western or Midland counties in Ireland. Five participants were recruited from 140 individuals who completed the WWA Program through a postal invitation to a subset of participants of the WWA programme. See table 1 for demographics of the participants included in the study.

Table 1: Participant demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age / Range</th>
<th>Employment status</th>
<th>Length of time since last employment</th>
<th>Type of work</th>
<th>Education level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evelyn</td>
<td>61</td>
<td>On disability payment</td>
<td>4 and a half years</td>
<td>Healthcare worker</td>
<td>Third Level</td>
</tr>
<tr>
<td>Bernie</td>
<td>40s</td>
<td>Employed</td>
<td>Currently working on reduced hours</td>
<td>Sedentary work</td>
<td>Third Level</td>
</tr>
<tr>
<td>Kate</td>
<td>47</td>
<td>On illness payment</td>
<td>14 months</td>
<td>Healthcare worker</td>
<td>Third Level</td>
</tr>
<tr>
<td>Sophie</td>
<td>59</td>
<td>On disability payment</td>
<td>15 years</td>
<td>Sedentary work</td>
<td>Third Level</td>
</tr>
<tr>
<td>Áine</td>
<td>50’s</td>
<td>On disability payment</td>
<td>6 years</td>
<td>Manual work</td>
<td>Secondary level</td>
</tr>
</tbody>
</table>

Data collection
Semi-structured audio recorded interviews were carried out with each participant by an Occupational Therapy student. The researcher followed an interview guide based on the research aims. The use of semi-structured interviews enabled the participants to give descriptive accounts of their experience. The researcher also used probing techniques and follow up questions to explore the topics in-depth with the participants (Merriam 2002; Bryman 2008). The interviews lasted for approximately 45 minutes. All recorded data were transcribed verbatim.

Data Analysis
Data were analysed using thematic analysis, by drawing connection within and between the participants, using the six stage guide as described by Brun and Clarke (2013). In the first
phase, all data was fully transcribed and entered into NVivo 8. A semantic approach was adopted by creating initial codes identifying aspects of the data that relate to the research question. The initial codes were then refined by identifying categories and links between them to develop preliminary themes. The themes were reviewed to ensure they had internal and external heterogeneity as described by Patton (2002). The themes were defined and named and the researcher wrote up the themes to finalise the analysis (Braun & Clarke 2013).

**Trustworthiness**

Several strategies were incorporated to increase the trustworthiness of the study. The use of thematic analysis ensured that the interviews are refined and refocused several times to gain a deeper meaning of the lived experiences of the individuals (Babbie 2010). Direct quotes were used to allow judgement of applicability and transferability of findings to other settings making this study internally consistent (Silverman 2005). Data collection and transcriptions were carried out by one person who was not involved in the delivery of the program. This aimed to prevent bias, ensure participants gave honest answers, and contributed to the consistency of the study (Bickman and Rog 2009). The researcher was reflexive throughout the thematic analytical process and interpreted the meaning of the words from the participants as intended (Green and Thorogood 2014). An audit trail on the procedures for analysing data is provided for the reader adding transparency to the study (Braun & Clarke, 2013).

**Ethical Consideration**

In 2013, approval was sought and granted from the University of Limerick Education and Health Science Research Ethics Committee for the recruitment of people with arthritis/MSD’s to the WWA program. Informed consent was obtained from all participants before they began the larger program. Separate informed consent was obtained from the participants of this study. Participants were recruited to the program on a voluntary basis, therefore respecting their right to self-determine their own participation (Hennink et al 2010). The identity of the individuals was protected with the use of pseudonyms (Silverman 2000).

**Results**

Based on this process of analysis, five themes emerged from the data:

**Theme 1: Experience of the therapeutic relationship with the Occupational Therapist**
All participants described a positive relationship with the therapist. Five elements were significant in this relationship: trust, being listened to, being understood, feeling cared for and supported. Trust was described by all the participants as a feature of their relationship with the therapist, describing the relationship as being “open and honest” (Áine) and enabling a safe space for them to discuss their feelings and current situations. Participants described the therapists reassuring and calming nature as being important in establishing a trusting relationship: “I was meeting someone who reassured me that they have seen it all before, and this is manageable and treatable and I trusted her” (Kate).

Almost all participants’ positivity evaluated the understanding nature of the therapist, stating that the therapist’s previous experience in the area and understanding of the impact of arthritis was very reassuring: “She could relate to our condition and this was a nice feeling having someone who really understood” (Sophie).

The experience of being listened to was described by the participants to reduce the feeling of isolation and make them feel supported: “It was nice to be able to talk to someone who was interested and cared because I don’t see anyone and I find myself thinking about it all in my head” (Evelyn). Two participants described this experience in contrast with interactions with other people: “You feel like you tire people out talking about it so I’ve kind of stopped but it’s nice talking to somebody who is actually interested and wants to help” (Sophie). Participants reported feeling supported by the therapist through the use of an inclusive approach, along with graded tasks: “she approached me and said the idea is you are going to return to work but we are going to have to deal with a few hurdles before you actually get that far. It was brilliant, she came down to my level and put me at ease” (Kate).

The feeling of being cared for emerged as a common experience across all accounts. Examples of care included; being asked about their condition, the therapists investment of time in the treatment and the relationship with the therapist: “It kind of feels nice that people care enough about your condition to ask you these questions too” (Bernie).

Theme 2: Positive experiences of therapy in the home and provision of an individualised service
All participants identified the experience of therapy in their home and the individualised service as a positively unique feature of this program. Participants acknowledged the
flexibility of the therapist as a facilitating feature: “you know everything was convenient for me to meet her” (Kate). One participant described the experience as a “luxury” (Bernie), similar to other participants reports who felt the experience reduced the need to rush, it was less stressful and more convenient for them: “it was the convenience of it was brilliant, she was able to come to my house, that was really good because you get worn out from appointments” (Bernie).

Almost half of the participants found the individualised tailored interventions very beneficial: “the follow up literature that she provided was tailored towards my own difficulties and it was all very reassuring” (Bernie). In contrast, one participant indicated that she would have favoured a group session as the support of others would have been more valuable to her following the intervention: “other people in the same position as myself to meet up and support each other, that would have been nice” (Sophie).

Participants reported feeling more motivated as a result of the therapists involvement. The relationship encouraged them to carry out the suggestions made by the therapist as there was a “timeline was created” (Sophie). They felt ‘knowing that the therapist would be asking” was motivating and “someone pushing [them] to do the suggestion” (Evelyn) increased the feeling of responsibility. One participant explained how the motivation impacted on other aspects of her life: “it would encourage you to get up and do things then…so it gave me a bit of motivation to get up and get out there and join something.” (Áine)

Theme 3: Learning about condition, self-management and services
Most participants reported that the advice and strategies the therapist gave were crucial in improving their functioning on a daily basis: “Yes she was very good to help with what I was having problems with, small things, she made great suggestions” (Sophie). Two participants felt that having someone to provide them with the appropriate literature was the most beneficial aspect of the program: “The convenience of someone bringing that to you rather than you searching for all the information yourself, it wears you down” (Áine). Most participants expressed positivity towards their learning on self-management, carrying out meaningful and normal activities, and managing their emotions. Another participant reported the: “Increased awareness about supports available was the most beneficial part of the program” (Kate).
Two participants highly valued the support the Occupational Therapist gave them in seeking information on their benefits and entitlements: “It was great getting to know what you’re entitled to and being aware about the different benefits and how to access them” (Áine). Two participants reported to greatly appreciate the onward referrals made by the Occupational Therapist to other health professional to provided further input regarding pain management and provision of equipment: “she organised another Occupational Therapist to call to my home to do some assessments, and that Occupational Therapist got me a few little helpful pieces of equipment” (Evelyn).

Theme 4: Experience / participation was influenced by low expectations of RTW
Many of the participant’s experiences were influenced by their low expectation of RTW when they signed up for the program. Four out of the five participants suggested that their main aim for taking part was to obtain further information for managing their symptoms of arthritis, to improve their occupational performance, and to be linked in with supports available: “I said this might help me pick up some tips or points from just talking to somebody about arthritis” (Áine). Two participants referred to the fact that they can never work again with their arthritis and RTW was not an option: “She spoke about exploring RTW but I can’t work with arthritis” (Sophie). Similarly one participant felt that RTW was not a consideration due to her age: “I would never go back at my age” (Áine).

All participants expressed an interest in voluntary work and the possibility of RTW/education, however, very few were interested in exploring this further: “Yes going back to do a course would be great but transport would be a problem so it would be too much hassle” (Evelyn). Further to this one participant was already involved in voluntary work and another had negotiated her own RTW with her employer prior to the commencement of the program, and therefore, it was not a necessary achievement from the program.

Theme 5: Occupational and other outcomes of participation in the program
One participant reported to having a very positive experience of engaging in the program as she was successful in returning to work: “I’m back working, 25 hours per week and I’m back working in a smaller environment, that’s exactly the request [the therapist] asked for in the letter she sent on my behalf” (Kate). Kate further reported how easy this transition was made as the therapist did all the negotiations on her behalf. She acknowledged the impact of the
program on her life and described significant improvements in her family life: “everything really improved in my life when I got back to work, it was my goal” (Kate).

Almost all of the participants described improved time use and occupational performance as a result of the therapists validating their fatigue and the provision of education and management strategies on their condition: “I feel like I spend less time battling the tiredness now and I can be more productive with the other times in the day” (Sophie). Participants felt this increased acceptance and awareness of their ability was a significantly positive outcome of the program. Two participants described improvements in their occupational engagement due to improved self-esteem and fatigue management. They expressed their increased confidence in reengaging in previous occupations, meeting people and socialising: “I’m getting there, I do love meeting everyone again, and doing all the jobs a mother should be doing. I feel better in myself for it” (Kate).

The five core themes analysed suggests VR with an Occupational Therapist was beneficial for these clients. The interventions provided the participants with resources and suggestions that proved to be helpful in their everyday lives.

**Discussion**

The importance of the therapeutic relationship as identified by this research reflects perspectives from previous qualitative studies (Palmadottir 2003; Morrision & Smith 2013). All five features of this relationship identified by participants; trust, understanding, being listened to, being cared for and being supported by the therapist, are reflected in the principles of a therapeutic relationship as defined by Cole and McLean (2003). Appreciation of the importance of the therapeutic relationship is also in line with theoretical underpinnings of Occupational Therapy (Taylor 2008).

Research shows, clients significantly value the quality of the relationship formed with the therapist and believe it is central to their experience of Occupational Therapy (McKinnon 2000). Consistent with the findings of this study, the success of therapy was described by D’Cruz *et al* (2016) in a small scale qualitative study, as being based on the development of trust and respect through a process of listening, being cared for, education and development of rapport. A number of studies indicate the quality of the relationship with the therapist, leads to increased patient satisfaction, motivation to achieve their goals and functional outcomes (Martin *et al* 2000; Tickle-Degnen 2002; Doig *et al* 2009). Therefore, the strength
of the therapeutic relationship is a determinant to the success or failure of therapy (Cole and McLean, 2003; Taylor et al 2009).

A central feature of the participant’s experience of the program was engaging in therapy in the home and receiving individualised interventions. The findings of this study are in keeping with McWey (2008 ) and Jones et al (2006) who found having a skilled professional coming to their home; very supportive, more personalised, engaging and motivating (Doig et al 2011). Similarly, in other studies, the home environment was described as a familiar and relaxed setting which invoked a sense of ownership and reduced power imbalance, in which the patients could be themselves, allowing for greater engagement (Sezaki and Bloomgarden 2000; Trialists 2004; Prince et al 2015). However in contrast, other accounts describe the experience of the therapist coming to the home as ‘invading’ and ‘stressful’ (McWey 2007), and, similar to the report of one participant in this study, participants felt they would prefer group therapy to increase socialisation.

The experience of learning self- management was positively evaluated in this study and its findings are reflected in other studies where increased self-efficacy in managing illness, increased knowledge and behaviour in self-management, and improvements in energy and motivation were reported (Lorig 2000; Siu et al 2007; Harvey et al 2008; Ellis 2010). The aim of self-management coincides with the primary aim of Occupational Therapy, as it strives empower clients to be actively involved in managing their health issues in order to conduct an active and satisfying life (Wilcock 2006; Taylor and Bury 2007; Ellis 2010). Self-management of chronic conditions is seen as a leading solution to the increasing demands made upon rehabilitation services (O’Toole et al 2013). There is a growing policy emphasis on self-management as an essential component of musculoskeletal chronic care models (Hoon 2015). Self- management is recommended as a foremost treatment approach when working with people with MSD’s. Across the literature on self-management and within this study, it is evident that Occupational Therapist are effectively implementing this approach and it is highly valued by participants (Palmadottir 2006; Randles 2009).

Throughout this study, participants reported low expectations of returning to work. There are a number of known predictors of successful return to work including; younger age, good working relationships and attitudes, higher education, employer work accommodations, vitality and self-motivation (Clayton et al 2011; Abasolo et al 2012). However in contrast,
this group, were older, had reduced health, had little motivation and low expectations of returning to work. A number of authors have reported that outcomes of therapy are largely connected to the patient’s expectations (Andersen 2014), and these findings are mirrored in this study. Lack of acceptance of the condition, loss of hope, and reduced motivation can lead to little or no ability to form goals or make a change (Conaghan 2015). Interestingly in a large scale qualitative study including 738 participants investigating ‘factors associated with successful VR in Sweden’, Marnetoft et al (2001) reported, unemployed people are partly disregarded in the rehabilitation process and are more difficult to rehabilitate than employed people. It is possible that the little research surrounding people’s experiences of rehabilitation with this group may have in fact led to the limited success in their rehabilitation. Patient expectations significantly affect outcomes in therapy and participants in this study had very low expectations about their capacity to work.

While most of the outcomes of this study were a variety of occupational non-vocational outcomes, one participant reported returning to work after the programme. Increased understanding of the condition, improved self-management, an ability to advocate in the workplace and increased mood were also identified as beneficial outcomes of the VR program. These outcomes were parallel with those in the literature on VR and chronic conditions which demonstrated the value of VR and Occupational Therapy in supporting individuals to return to work and improving quality of life (Young 2010; Jellie et al 2014).

Although many didn’t receive positive outcomes in terms of returning work, they described alternative effects across the broad range of their daily activities which was in keeping with the domain of the Occupational Therapy profession in supporting health and participation in life through engagement in occupation (Roley 2008). Improved occupational participation, increased awareness of ability, improved time use and fatigue management enabled increased engagement in activities of leisure and productivity. Occupational balance and its benefits are well researched in Occupational Therapy, as Molineux (2004) and Pierce (2003) both describe the importance of developing a balance of time including elements of productively, pleasure and restoration in order to achieve health and well-being.

**Limitations**

It is acknowledged that the data is only representative of a small number of people making it difficult to generalise the findings to a wider MSD population. It is limited by gender as all
participants were female therefore limiting the representation of males in the research. The quality of this study was limited by the nature of using qualitative interviews. Member checking was not carried out within this study therefore questioning its rigour and trustworthiness (Babbie 2010). The recruitment process of this study was challenging, as it may be possible that this group were over-burdened having already completed the program and engaged in a number of measures and questionnaires. This study would have benefited from stratifying participants in order to recruit people with a broader range of outcomes. There were very few criticisms of the study expressed by the participants in the interviews which may be influenced by sociable desirability and the researcher’s perceived connection with the university who ran the WWA programme (Manning and Kunkel 2013). The researcher may not have been perceived as independent and unbiased by participants therefore limiting the information they disclosed. Furthermore, the researcher’s limited experience as a qualitative researcher may have influenced the outcomes of the study.

**Implications for future research**

A larger sample size and carrying out a longitudinal study including both genders would allow for more in-depth information and a broader range of outcomes of the WWA program. In order to develop this study further, stratifying the participants and investigating people’s experiences across the processes of VR would highlight the different outcomes at the different stages giving more accurate accounts of the interventions. Including different forms of data collection such as a focus group, could help the participants to openly discuss their feelings and inspire further thoughts regarding their view on effective interventions. A phone interview may also be used in order prevent any influences of social desirability by the participants, and obtaining more accurate results. VR to prevent job losses in rheumatic disease is shown to be effective across the literature (Hammond 2008), however once people are unemployed, return-to-work intervention are less effective and this warrants attention. These new findings could provide a valuable contribution to the development of Occupational Therapy led VR interventions however further research is required to establish effectiveness of VR developed by Occupational Therapists for this group.

**Implications for Occupational Therapy practice**

This study underscores the importance of the therapeutic relationship as described by Taylor (2008) and emphasises the need for therapists to be cognisant of developing an honest and trusting relationship with the patient, in order to achieve successful outcomes in therapy. It
further highlights the need for the therapist to be aware of the patient’s expectations at the start of therapy (Wright-St Clair 2001), and they should elicit these in the goal setting process and ensure the clients beliefs, preferences and expectations are a central part of the process to aid successful engagement and outcomes. The majority of the participants reported low levels of motivation. It may be advantageous to explore interventions to address this low motivation before the beginning of a program through engagement in interventions such as motivational interviewing. This aims to elicit behaviour change by helping clients to explore and resolve ambivalence (Miller and Rollnick 2012). Furthermore, Creek (2007) explains, by giving clients the opportunity to have new experiences by engaging them in undemanding activities can begin a process towards actions that help them build their own lives. This study supports the benefits of working with people in their own homes and offering individualised service which is typical of Occupational Therapy practice. It fosters empowerment and motivation and should be an approach considered by all Occupational Therapists when working with vulnerable groups. Occupational Therapists are investigators of change. It is imperative that Occupational Therapists conduct research into the efficacy of their unique contribution to VR program for peoples with MSD’s (Robinson et al 2011). This could be completed through the use of outcome measures or assessment tools for collaborative goal setting with clients in order to investigate the elements of VR that are successful.

Conclusion
This study evaluated participant’s experience of taking part in the WWA program. Five core themes were identified through qualitative interviews with participants. The central themes identified consisted of experiences of the therapeutic relationship with the Occupational Therapist, therapy in the home and individualised services, self-management and service provision, low expectation of returning to work and vocational and broader occupational outcomes following the program. As discussed, these findings are reflective of the wider experiences of people with chronic conditions who participated in rehabilitation programs. These findings stress the need for continued exploration or people’s experience of Occupational Therapy led VR in order for Occupational Therapists to demonstrate the efficacy of their unique professional contribution in VR and chronic conditions and to design successful interventions to adequately meet the needs of these clients, as work has been documented to be the most effective way to improve well-being of individuals.


