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EDITORIAL

Linda Penny, OTR/L, MA

Life Long Learning was always very important to me as a person. Following a volunteer stint in an orphanage in Romania, I learned about the wonderful world of Occupational Therapy. Emigrating to the USA, I studied at the University of Illinois at Chicago, USA where I had the privilege of meeting and studying under some of the finest tutors in the world, including Gary Kielhofner. As a therapist in America, the engagement in Continuing Professional Development (CPD) was not only encouraged, but mandatory through national and state legislation. I gained my Bachelors in Occupational Therapy and worked in the USA. When I returned to Ireland, I tried to incorporate CPD and Life Long Learning into my work and personal life.

I finished my Masters with the first published research on CPD in Ireland in 2004 and was invited by Odhran Allen to the AOTI CPD Working Group in 2005. That group developed the CPD portfolio that is still in use today. This CPD portfolio incorporates practical planning and recording tools to capture the full range of CPD activities. The Working Group became the AOTI CPD committee and I have been chairperson since then.

So much has changed in the intervening years. As far back as 2005 AOTI were planning, strategizing and developing our CPD needs. From the first HSCP Act 2005 and then the HSCP (Amended) Act 2012 it was clear that our profession was going to be regulated.

CPD is an essential part of every professional’s working life. AOTI recognises the need for all occupational therapists to embrace CPD as an integral part of their professional lives. The development of the CPD portfolio and subsequent points system ensure that best standards of practice will be maintained for our members.

The CPD points system was developed which complements the information in the CPD portfolio. It is based on a “30 points” process, and it gives plenty of scope for everyone to accumulate points across a variety of activities. If your CPD activity is not listed, AOTI encourages you to keep a written record of these activities which should illustrate the type of learning achieved – be it solidifying or complementing what you already know or any new learning that has been gained. The points system has been published, and it will very nicely complement CORU’s CPD requirements. While the CPD requirements for CORU have not yet been formally made available, AOTI members can rest assured that by engaging in our CPD system you will be fully prepared for State Registration. A new Audit committee is currently being established to begin auditing AOTI members in 2015.

Some of our goals for the coming months include:
- The development of an online system whereby therapists will be able to record and track their CPD activities and points. Imagine with a click of a button an AOTI member will be able to print out their reports and documentation, in the event of an audit!
- Ongoing provision of workshops and training courses
- Finalisation of the Audit committee
- Establishing a system of accreditation for courses / course providers
- Finalisation of the Return to Work Policy

I have enjoyed my work to date on the committee. I have met so many people who are enthusiastic and committed to achieving and maintaining high standards, both in their work and in our professional body. For many of our members who have worked abroad, they have had to engage in CPD and may have even being audited but they are still around to tell the tale! Please stop worrying fellow therapists. Onwards and upwards.

We are a hardworking, committed bunch of therapists on the AOTI CPD committee, ably assisted by the AOTI CPD Development Officers. We hope you have enjoyed our work to date, and will continue to support and engage in all the work of AOTI.

Linda Penny, OTR/L, MA

Members of Committee (May 2014):
Linda Penny (Chair); Sarah Lee (Director of Professional Development); Margot Barry (maternity leave), Denise O’Shea, Carmel Lalor, Ailin Farrell, Tara Blanchfield, Louise Lawlor

Patricia Regan resigned from the committee in order to fulfill the role of WFOT delegate. We wish her every success and thank her for her work to date.
PAEDIATRIC RESEARCH: EXPLORING PARENTS’ EXPERIENCES OF PROVIDING PARENTAL CONSENT

Jean Harrington, BSc Hons (OT), Occupational Therapist, Occupational Therapy Dept, St Pancras Hospital, London, NW10PE

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‘We’re responsible for the kids, and what we do now, will affect them in the future’ (parent)

ABSTRACT

Parental/proxy consent is permission freely given by an informed parent on behalf of the child to participate in research (Coyne, 2009; Neill, 2005). In Ireland, parental consent must be obtained in order to carry out research with a person less than 18 years of age. Few studies have been conducted which explore the experiences of parents who have made the decision to grant parental consent for research purposes.

This paper describes a qualitative exploratory descriptive study undertaken to investigate parental considerations in making this decision and to explore their experiences of the informed consent process. The experiences of five parents (aged 39-45 years) who had granted consent for their child to engage in research that was not of direct risk and/or benefit to the child were investigated through semi structured interviews. Thematic analysis revealed three themes: safety of the child; altruism and the child’s ability to consent. The findings provide insight into aspects of the informed consent process. Furthermore, core motivators and barriers to provide parental consent are identified. These findings can support Occupational Therapy researchers to enhance the recruitment and informed consent processes in the design of future research studies for parent and child.

KEYWORDS

paediatric research, parental consent, ethical practice, consent.

INTRODUCTION

The United Nations Convention on the Rights of the Child (UNCRC, 1989) recognises young people’s rights and the importance of consulting young persons with issues which concern them. These rights play a significant role in relation to researching with children. In Ireland there has been an increase in health research with and for children (Department of Health and Children (DoHC), 2009). Furthermore, research in early childhood has doubled since 2003 compared to the previous decade (Centre for Early Childhood Development and Education (CECDE), 2007). Consequently, national guidelines for ethical practice have been developed to ensure research follows best practice and that children are protected (Department of Children and Youth Affairs (DCYA), 2012; DoHC, 2004).

In Ireland, parental/proxy consent must be obtained in order to carry out research with a person under the age of 18 years (Coyne, 2009). Parents are viewed as ‘gatekeepers’ (Ireland & Holloway, 1996). The assent of the child i.e. the child’s positive agreement may also be
sought but is not a requirement (DOHC, 2009; McIntosh et al., 2000). There is currently a debate in Ireland regarding this requirement to gain parental consent as it does not acknowledge a child’s right to and ability to make his/her own decisions (Coyne, 2009; DOHC, 2009; Veale & Barry, 2004).

International research on the topic of parental consent primarily focuses on invasive research e.g. randomised controlled trials (RCT) or vaccine trials (Chappuy et al., 2006; Frank, Winter & Oulton, 2007; Rothmier, Lasley & Shapiro, 2003). Studies highlight paediatric recruitment as a challenging process and one of the most difficult barriers in children’s research (Nicklin & Spencer, 2004; Sammons, Atkinson, Choonaara & Stephenson, 2007; Watson, 1999). As few studies have explored parental consent in non-invasive studies it is not known to what extent the recruitment issue would still apply. As a result, it becomes increasingly important to understand why parents give consent for their child’s participation in research (Boccia, Campbell, Goldman & Skinner, 2009; Caldwell, Butow & Craig, 2003; Tait, Voepel-Lewis & Malviya, 2004). This issue has importance in the study of children’s occupation, as qualitative, non-invasive research is dominant as an approach in occupational therapy research (Frank & Polkinghorne, 2010).

This study was undertaken to explore the experiences of Irish parents who have made the decision to grant parental consent for non-invasive research. Non-invasive research was defined as research that is not of direct risk and/or benefit to the child. The research study which the participants’ children engaged in was part of a broader study with the aim of gathering Irish normative paediatric data. It involved administering a sensory integration structured clinical observations tool to typically developing children between nine and thirteen years of age.

LITERATURE REVIEW

The databases of BioMed, PubMed, BMJ journals and Sage publications were utilised in order to explore a broad range of literature. A comprehensive search was conducted to find literature published from 1985 to 2012.

A significant challenge in researching with children is that another person (the parent) is responsible for giving consent on behalf of the child (Caldwell et al., 2003; Shilling & Young, 2009). Studies have shown that parents consider research involving themselves, where they can exercise autonomy, very differently to paediatric research in which they are responsible for another person (Chappuy et al., 2006). For example, Zikmund-Fisher, Sarr, Fagerlin and Ubel (2006) asked 2,399 people to imagine themselves in various different roles e.g. parent; child; doctor; in a hypothetical medical situation. From the findings, the researchers concluded that ‘What we choose for ourselves is not always what we would choose for another’ (p. 622). Therefore, the challenge in giving parental or proxy consent appears to lie in being responsible for the well being of another person.

One of the most important considerations that parents identified when making this decision is the possible risks and benefits of the research to their child (Caldwell et al., 2003; Chappuy et al., 2006). In a study related to vaccines, Chantler et al. (2007) identified that mothers believed that children should only take part if medical benefits outweighed potential risks. This demonstrates that balancing risk and benefit is central in a parent’s decision to provide parental consent and understanding how parents ‘weigh these factors’ is important for researchers (Boccia et al., 2009, p. 92).

Altruism is another significant consideration in parental consent (Hoehn et al., 2005; Liaschenko & Underwood, 2001). In studies about parental motivation, parents who consent to engaging in research were found to be motivated by two factors: a benefit for children along with a contribution to science (Sammons, Atkinson, Choonaara & Stephenson, 2007). However, studies also show that parents first consider benefits of the research to their own child before they consider altruistic factors (Rothmier et al., 2003; Shilling & Young, 2009).

Research has identified parents have experienced ethical dilemmas in consenting also. Studies have shown that parents can feel obliged to participate in research (van Stuijvenberg et al., 1998) or feel they have no other option (Liaschenko & Underwood, 2001) or simply follow what their doctor advises (Harth & Thong, 1995). Findings highlight a need to improve the informed consent process in order to aid parents in making this challenging decision (Eder, Yamokoski, Wittmann & Kodish, 2007; Frank, Winter & Oulton, 2007). Methods have been suggested on how to improve the informed consent process for parents: the need for clear and sufficient information presented in a balanced manner (Boccia et al., 2009; Chappuy et al., 2006); increased time for decision making (Eder et al., 2007) and allowing parents to specify stipulations for their children e.g. a child-orientated environment (Hadley, Smith, Gallo, Angst & Knaff, 2008). In fact, Swartling, Helgesson, Hansson and Ludvigsson (2009) surveyed 4,000 parents on their views on a child’s right to participate in non invasive research. Child autonomy and decision making ranked lowest in what they consider when making this decision.

The literature review demonstrates that for invasive research studies, parents consider the risks and benefits to the child as well as altruistic deliberations, when making this challenging decision. Furthermore, parents have experienced difficulties in making informed decisions about consent and have felt influenced by power relationships in the research process. Further investigation is warranted into parents’ experiences of providing consent particularly for non-invasive research studies as well as their views of the informed consent process.

The aim of this study was to give a rich account of the experiences of parents who consented their healthy child to non-invasive research in order to:

a) give health professionals an understanding of parental deliberations when making this decision
b) assist researchers to enhance the recruitment and informed consent processes in future studies.
METHOD

Research Design
This study used a qualitative approach as the aim was to examine parental experiences and ‘discover the personal meanings involved’ (Polgar & Thomas, 2008, p.84). Qualitative research is often the first step in exploring a particular topic (Luborsky & Lysack, 2006) which is important to this study as the issue of parental consent for non-invasive research has not been given a great deal of attention in the literature to date.

An exploratory descriptive design was used for this study as it aims to convey concepts which can then be used as important sources of ideas and information for future research (Melnyk & Fineout-Overholt, 2005; Sandelowski, 2000).

Ethical approval was granted in 2010 from University College Cork/Clinical Research Ethics Committee of the Cork Teaching Hospitals.

Participants
All parents who had consented for their child to participate in the non-invasive research study were invited to participate in this study, i.e. a cluster sample was utilised (Dickerson, 2006). These parents were all from a small rural community in West Munster. Informed consent was achieved through an information meeting and consent forms were returned. Parents who were Irish nationals and were resident in Ireland for at least five years were included in the study in order to obtain findings bound in an Irish context. Six participants were randomly selected from the cluster to form the sample. This number was based on balancing the need to get sufficient information and opinions, with time and resource limitations of the researcher. Verbal contact was made with the participants to provide an opportunity for questions and a time and place to carry out the interview was arranged at each participant’s convenience. One participant withdrew from the study due to health reasons leaving five participants in total: one male and four females aging in range between 39 and 45 years, with a mean age of 42 (Table 1).

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Marital status</th>
<th>Child’s age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mauro</td>
<td>Female</td>
<td>42 years</td>
<td>Irish</td>
<td>Married</td>
<td>9 years, 11 months</td>
</tr>
<tr>
<td>Nora</td>
<td>Female</td>
<td>45 years</td>
<td>Irish</td>
<td>Married</td>
<td>12 years, 11 months</td>
</tr>
<tr>
<td>Orla</td>
<td>Female</td>
<td>39 years</td>
<td>Irish</td>
<td>Married</td>
<td>9 years, 9 months</td>
</tr>
<tr>
<td>Maureen</td>
<td>Female</td>
<td>41 years</td>
<td>Irish</td>
<td>Married</td>
<td>10 years, 1 month</td>
</tr>
<tr>
<td>Peter</td>
<td>Male</td>
<td>43 years</td>
<td>Irish</td>
<td>Married</td>
<td>10 years, 11 months</td>
</tr>
</tbody>
</table>

Table 2: Participants’ demographic information including pseudonyms

Data Generation Method
Semi-structured interviews were employed as this method allows the interview process to be flexible and enables the use of guiding questions and memory prompts for the novice researcher (Hewitt, 2007; Moore, 2000; Rapley, 2001). An interview guide was used to ensure key topics had been covered (Taylor, 2005) and hypothetical case scenarios were also utilised to elicit further discussion (Brockopp & Hastings-Tolsma, 2003; Gribich, 2003). One pilot interview was carried out with a candidate of similar characteristics to the sample in order to pilot the question guide and practice interviewing skills (Sampson, 2003). Minor alterations were made to the questions following this for clarity purposes.

Interviews were conducted in a private room in a convenient location for the participants (e.g. the school or the participant’s home) and took up to 45 minutes per participant. Practical steps were taken to ensure confidentiality of the participants in line with the Data Protection Act 1988 and the Amendment Act 2003. These methods included but were not limited to: only members of the research team had access to the data; data was stored in a locked file cabinet and a password-protected electronic file; names for the data were removed and replaced with pseudonyms, used throughout this paper.

Data Analysis
The interviews were audio-taped and transcribed verbatim by the researcher (Carpenter & Suto, 2008). Thematic analysis was used in order to identify key issues (Green & Thorogood, 2004). The transcripts were read a number of times and recurrent concepts were recorded in the margin of the transcripts. This was continued until data saturation was achieved. Key concepts and quotations were identified and extracted from each transcript. Concepts that were most frequently emphasised by all participants from across the transcripts were grouped together to form sub-themes (Pope, Mays & Popay, 2007).

Strategies were employed to ensure criteria for trustworthiness. To ensure credibility, member-checking was employed (Ballinger, 2004) whereby telephone contact was made with the participants following initial data analysis, giving the parents an opportunity to comment on the findings. Findings from the overall study were sent to participants again, as a second level of member checking. Thick description is utilised in this paper to enable readers to decide upon the transferability of the study (Bryman, 2004). Regarding confirmability, the strategy of reflexivity was employed. The researcher maintained a journal throughout the process to acknowledge her own ‘assumptions and ensure findings are reflective of the participant’s...perspectives only’ (Curtin & Fossey, 2007, p.93).

RESULTS
Sub-themes were drawn from the participants’ own words and collapsed to form major themes (Figure 1). Key motivators and barriers to providing consent were also identified. The themes are discussed in more detail below. Pseudonyms are used and direct quotes from the parents support the findings.
Theme 1: Safety of the Child

The safety of the child and understanding any risks that may be involved in the research protocol was dominant in all five parents’ decisions. Participants for the non invasive research study were recruited via a local primary school and the protocol itself was carried out in the school environment. All the parents identified that the role the school played in the research study ensured them that their child would be safe:

‘I suppose when things come through the school like, you feel that they are more legitimate. I suppose you’re aware that the teachers are in the background and it’s a safe environment...I think it just brought an extra safety element into it really’ (Maureen).

Parents felt happier when the principal and teachers understood and were involved in the research project:

‘I suppose I felt that if the teacher was allowing it into the school, I knew that it was alright to do it. Maybe if it was something that came in through the post, I might have ignored it, you know? Whereas, I put all my trust in the teachers to look after my children everyday so I would presume that they would never put them in danger. Yes, when they were allowing it into the school, I knew it was fine to do it’ (Maureen).

Four out of the five parents reported that they preferred the researchers were female and were unsure if they would consent their children to the study, if the researchers were male. The parents stated that they felt this view was unfair for male researchers but nonetheless recognised it as an important consideration when questioning the safety of a research study:

‘I suppose everyone is heightened with the media and everything. If there was a male person with a group of girls, you’d like if there was a second adult just for safety really. You can’t go around thinking that you can’t trust everyone...But at the same time I think you’d be more inclined to trust a woman with a group of children’ (Maureen).

However the parents reported that if they could put in stipulations to allow a female to be present, they would be more likely to consent their child to the study.

Receiving results of and feedback from the study was a common sub theme amongst all the participants which they felt made the study safer for their children:

‘Getting feedback is important. It’s hard to provide information or do something for people if you don’t know what will be done with that information. So to get the results or information from the results is vital as to what you want to put forward then again in future research’ (Peter).

Theme 2: Altruism

Altruism was a prevalent theme identified by the parents when making this decision. Though the study was not of direct benefit to their own children, the parents felt that it could assist other children:

‘I think it’s important that we help it (research) now. Even though we don’t need it at the moment, it might benefit somebody else’s child. And please God there’ll be grand children down the line and you just never know when you might need it. So I think it’s important that you support it now’ (Orla).

All five parents had a positive attitude towards and recognised the need for continued research and education in our society:

‘We thought it was more educational for somebody else rather than ourselves, research that somebody could learn something out of. It mightn’t be to our good immediately but it might be to someone, sometime. I’d like to see that there would be some good to be got out of it for future education’ (Peter).

Theme 3: Child’s ability to Consent

All the participants reported that whether or not the child wanted to partake in the study played a role in their decision. The parents gave their children the autonomy to make this decision for themselves:

‘Well, she wanted to do it. But it’s just I suppose, the innocence again, just wanting to try something different. She read it and I said well, if you want to do it, ok. I didn’t force her to do it, I didn’t mind. If she wanted to do it, no bother. And she didn’t half think about it. She wanted to do it.’ (Nora).

Three of the parents felt that their child was informed and had the ability to consent to research which influenced the parent’s decision in providing parental consent:

‘She’s mature enough to decide and do her own thing. She’s individual enough to maintain her individuality when she’s doing it (the research) and is not easily influenced by peers or others’ (Peter).

Sub-Theme: Informed Consent

The five participants in this study were questioned on their views of the informed consent process. All the
parents described that they feel motivated to provide parental consent when detailed information on the purpose of the study is provided. Information should be presented in a thorough yet succinct, low-tech, reader-friendly manner. Written information on the protocol is preferred first, followed by verbal information with the opportunity to ask questions, perhaps over a telephone call. The majority of parents wanted the child to have a voice in the decision, aided by child-friendly information:

'I was very impressed because other times, if there was some consent form you had to sign, there generally wasn’t a lot of information behind it whereas I felt there was a lot of information with this and you know... well it made me sit down and read it and I found it interesting' (Maura).

Barriers to providing parental consent included not receiving enough information on the protocol. In the event of this occurring, the majority of parents reported that they would seek advice from someone who was knowledgeable on the topic or alternatively they may refuse to provide consent. Having a previous negative experience of research e.g. the information letter being different to what the child actually did, was another reported barrier to providing parental consent.

The motivators and barriers to providing parental consent identified by the participants are presented in Table 2, supported by direct quotes.

Table 2: Motivators and barriers to providing parental consent

<table>
<thead>
<tr>
<th>Motivators to Providing Parental Consent</th>
<th>Barriers to Providing Parental Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>A lot of succinct essential information</td>
<td>Previous negative experience of research e.g. consent was not fully informed</td>
</tr>
<tr>
<td>'There was an awful lot but it did cover everything. I don’t think you could have too much information' (Maura).</td>
<td>'It would make you weary. If you had something that bothered you about the last research or something you took part in and if you had questions mark it over; the next time you’ll be asked to take part in something you’d say well there was something I didn’t know the last time' (Maureen).</td>
</tr>
<tr>
<td>Written information followed by verbal information</td>
<td>Not receiving enough information</td>
</tr>
<tr>
<td>'To be honest, I like both. I like something I can sit down with and look at and I like to be spoken to and told about it, to have it explained to me...' (Nora).</td>
<td>'A lot of information is needed so it’s not as if you’re going into the unknown. It brings an extra safety element to it really' (Maureen).</td>
</tr>
<tr>
<td>Child friendly information and giving the child a voice</td>
<td>Topic and researcher completely unknown</td>
</tr>
<tr>
<td>'It was very friendly, there was nothing to be afraid of; I thought that was nice too because you know, sometimes kids look at a page and think it’s too much boring' (Maureen).</td>
<td>'I was made to be that I know nothing about the people or nothing about the subject' (Orla).</td>
</tr>
<tr>
<td>Researchers meet the needs of the participants</td>
<td>Use of rewards/incentives to consent</td>
</tr>
<tr>
<td>'You have to make it easy for people as well. It’s you who are doing the research so it’s you that have to come and meet people rather than people bending over backwards to suit you' (Peter).</td>
<td>'I thought that certainly there was no pressure whatsoever. You didn’t say oh really hope you will or anything. There were phone numbers and your names and details and the college. You knew if there was some kind of incentive or reward or something, it might make you think, oh they’re really pushing it here' (Maureen).</td>
</tr>
<tr>
<td>Examples of similar/previous research</td>
<td></td>
</tr>
<tr>
<td>'If it was possible to give some results of some previous studies in the past. It would give people the confidence that this has been done before and we are not the first people to do it' (Peter).</td>
<td></td>
</tr>
<tr>
<td>Low tech and reader friendly</td>
<td></td>
</tr>
<tr>
<td>'So yeah, I read through it but it was just, you know, I suppose when I’m not doing that course or I know nothing about it, some of it was a bit high tech for me' (Orla).</td>
<td></td>
</tr>
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</table>

DISCUSSION

Given the limited research to date on why or why not parents agree to consent their child to non-invasive research, this study provides insight into the experiences of parents in making this decision and their views of the informed consent process.

In this study, parents identified that the safety of their child was a primary consideration when making their decision, even though this was a non-invasive study. This finding is consistent with other research where the parent’s primary objective was to protect the child from harm (e.g. Caldwell et al., 2003). In this current study parents described aspects of the research study that assured them it was safe for their child to participate i.e. involvement of the school; receiving feedback and presence of female researchers.

The author recognises that the request by parents in this study to have a female present during a research protocol is non standard practice. Yet, is should also be noted that the male parent did not identify this as a specific safety consideration. In comparison to the literature, it is clear that parents consistently seek information on the safety aspects of a protocol when making the decision to consent their child to research (Pletsch & Stevens, 2001; Singhal, Oberle, Burgess & Huber-Okrainec, 2002).

Altruism was identified by all the participants as a motivating factor to provide parental consent. Chantler et al. (2007) in interviews with 34 mothers reported that a ‘social responsibility’ was the most quoted reason to provide parental consent for a vaccine study (p.315). The aspiration to help other children is a common theme in the literature (Edwards & McNamee, 2005; Hoehn et al., 2005). The concept of altruism, defined as ‘a motivational state with the ultimate goal of increasing another’s welfare’ (Batson & Shaw, 1991, p.108), is discussed in other disciplines to include sociology and psychology. Piliavin and Chang (1990) and Dovidio (1991) propose the ‘empathy-altruism’ hypothesis, meaning that empathy is casually related to prosocial behaviours. This hypothesis is similar to the participants in this study who empathised with other parents whose children are not typically developing and as a result consented their child to this study.

The parents in this study identified the importance of the child’s decision to partake in the study. Studies report that parents take the views and preferences of the child into account, particularly for older children (children over the age of 12 years), when making this decision (Caldwell et al., 2003; Miller et al., 2008). This study involved non-invasive research and older children (aged between nine and thirteen years). These may be the reasons why the child had a stronger voice in the decision making process. Contrasting literature identifies the burden of responsibility that parents feel in making this challenging decision on behalf of the child (Chantler et al., 2007; Rothmier et al., 2003).

The discrepancy of views within this study and the literature is representative of the ongoing debate that
exists on the child’s capacity to consent. Parents in this study recognised and valued the child’s right to consent. This contrasts with the current legal acknowledgement of the child’s rights in Ireland. In Ireland, parental consent must be obtained and assent of the child is sought at the researcher’s discretion for a child less than 18 years of age (Coyne, 2009). However in the U.K., consent is obtained from the parent and where the child has sufficient cognitive abilities to understand the research, assent must be sought (Neill, 2005). Hunter and Pierscionek (2007) proposed that Gillick competency be applied to certain research cases: this is when the child has sufficient intelligence to understand what is being proposed and as a result autonomous consent is sought despite the child’s age. Regardless of the ongoing discussion however, parents of this study still recognised the child’s right to and ability to consent which is clinically useful for future researchers.

The participants of this study also identified a number of motivators and barriers to providing parental consent (Table 2). In other studies, similar findings have also been reported. For example, in a study with 140 parents of children engaged in research, they recommended improving the informed consent process to include succinct, detailed information and provision of addition materials for parents (Eder et al., 2007). These findings match this study’s results even though the recommendations are for invasive research.

The study also found that if parents had a previous negative experience of research, they will be reluctant to consent to research again. This highlights how important it is to understand parents’ views of the research process, as parental consent is central to paediatric research. This finding reflects the National Children’s Strategy (DOHC, 2000) which aims for children to have their lives better understood as a result of research. By implementing some of the suggestions from this study into practice, parents may be more likely to provide parental consent to research and begin to accomplish this aim.

The overall results from the study mirror national and international guidelines on researching with children where there is an emphasis on involving children in the decision making process (DOHC, 2009; Neill, 2005; Veale & Barry, 2004). By applying knowledge from this study into practice, children may be more frequently consulted in matters which concern them, as recommended by these guidelines.

Limitations
The small sample size of this study may mean that the transferability of the findings to a wider population of Irish parents could be limited. However, the aim of this study was to gain an in-depth understanding into what parents consider when they make such a decision.

The participants were from the same county in Ireland. Thus, data collected is limited to this demographic.

The positive attitude towards research evident by the participants in this study may be over estimated as those who did not provide parental consent were not interviewed.

Four females and one male comprised the sample. It is unknown if gender biases had an impact on the findings.

These limitations must be considered when applying the results to practice however the findings are supported by literature adding to their credibility. The results of this study provide valuable information for future studies as well as adding unique findings to the body of literature.

CONCLUSION/RECOMMENDATIONS
The study sought to explore five parents’ experiences of providing consent for their child to participate in research. The findings provided knowledge and insight into the parent’s decision as well as motivators and barriers to providing parental consent for future researchers.

This study verifies earlier work on this topic; however, as the research protocol was non-invasive some of the findings were new to the body of literature. This has led to a number of recommendations for future researchers. It is suggested that researchers make clear to parents the level of risk involved and safety procedures involved in the protocol depending on the nature of the research. The findings also propose that researchers work appropriately with the altruism of parents by making clear the possible benefits the research may have for other children and for advancement in research while being mindful of potential issues of coercion, power and undue influence.

This study found that these parents valued their child’s involvement in the decision making process which is in line with current best practice. Irish health professionals are guided by recent policy developments to implement a rights-based approach in research where due attention is given to protecting the child and also protecting their rights to participate in research (DCYA, 2012). This will only happen with a shared understanding among parents and researchers of the child’s right to participate and have a voice in research. Suggestions are made that researchers provide a child-friendly consent form and information materials and that all efforts be made to work towards an authentic process of ‘doing research with’ rather than ‘researching on’ children. An essential part of this process is ensuring that children share in the decision to participate.

Finally, it is recommended that researchers are aware of the motivators and barriers to providing parental consent in order to work collaboratively with parents (Table 2).

Overall, these findings are relevant to client centred practice for occupational therapists as well as other health professionals. Client centred practice continually underpins our work whereby occupational therapists work in partnership with people receiving services, recognise client’s experience and knowledge and strive to meet clients’ needs (Canadian Association of Occupational Therapists, 2002; Law, Baptiste & Mill, 1998). This study has aimed to achieve these elements...
concerning the recruitment and informed consent processes in research studies.

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CARING FOR A RELATIVE WITH DEMENTIA: THE IMPACT ON CAREGIVERS’ OCCUPATIONAL PARTICIPATION

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ABSTRACT

Background: The numbers of people with dementia worldwide are growing rapidly. Informal caregivers provide support, enabling people with dementia to remain at home. Unfortunately, caregivers frequently experience restricted occupational participation and social interaction because of the demands of caregiving.

Objective: The aims of this research were to explore i) the daily occupations of caregivers of people with dementia; ii) how their occupations changed because of caregiving and the factors affecting change; iii) caregivers’ emotional responses to these changes and their perceptions of their own occupational balance.

Methods: A phenomenological study was conducted. Data were collected from three informal dementia caregivers through two semi-structured interviews with each participant, and analysed thematically. Credibility and trustworthiness were addressed through member checking, an audit trail and the use of a reflexive diary.

Findings: The overarching theme was occupational participation. Caregiving was identified as a daunting new occupation in the lives of participants. Two caregivers experienced occupational deprivation and imbalance because of caregiving, while the third caregiver managed to maintain occupational balance. Support from families, professional caregivers and respite centres enabled continued occupational participation among caregivers. The level of care required by the care receiver and the presence of behaviours that challenged limited caregivers’ ability to achieve meaningful occupational participation.

Conclusions: Occupational therapists are uniquely qualified to support people who experience restricted occupational participation in overcoming the challenges they face. It will be necessary for occupational therapists to expand their role to facilitate continued occupational participation and social inclusion of caregivers.

KEYWORDS

Dementia, caregivers, occupational participation, occupational balance

INTRODUCTION

Dementia is rapidly becoming a major public health concern, with significant costs to society and to informal caregivers (Gitlin, Hodgson, Jutkowitz, & Pizzi, 2010). The term dementia describes a group of diseases characterised by a progressive decline in cognitive functioning, affecting memory, thinking, behaviour, emotional control and the ability to perform everyday activities (World Health Organization & Alzheimer’s Disease International, 2012). In Ireland, there are currently approximately 41,470 people with dementia. It is expected that this figure will triple by 2041 because of the expanding ageing population (Cahill, O’Shea, & Pierce, 2012a). Presently, over 26,000 of the people with
the overarching aim of the Occupational Therapy process...participation in meaningful occupations has been deemed...Cohen et al., 2002; Donovan & Corcoran, 2010). Caregivers have been described as “hidden patients” (Gitlin & Corcoran, 2005, p.9), who frequently experience burden related to restrictions in social and leisure occupations (Black et al., 2009; Egan et al., 2006). Dementia caregivers may experience increased burden compared with caregivers of people who do not have dementia (Lilly, Robinson, Holtzman & Bottorff, 2012; Pinquart & Sorensen, 2003). It has been suggested that the severity of the care receiver’s cognitive impairment and particularly the presence of behaviours that challenge may result in restricted participation in meaningful occupations for caregivers, and heightened caregiver burden (Contador, Fernandez-Calvo, Palenzuela, Migués & Ramos, 2012; Gitlin, 2012; Pinquart & Sorensen, 2004).

Due to the increase of people with dementia, occupational therapists may need to enhance their services to offer more effective support to dementia caregivers (Hall & Skelton, 2012). Supporting caregivers may enable them to continue providing care while still maintaining engagement in other occupations, therefore reducing burden (Black et al., 2009). Further research into the occupational issues relating to caregivers is necessary to support the expansion of occupational therapists’ role (Hall & Skelton, 2012). The main purpose of this study was to gain an insight into the effects of caring for a relative with dementia on occupational participation.

According to the American Occupational Therapy Association (AOTA) (2008), caregiving involves providing direct care and supervision, as well as organizing alternative care for the care receiver when necessary. Caregiving can have both positive and negative outcomes for those providing care (Quinn, Clare & Woods, 2012). Many caregivers report satisfaction in providing support, and feel that it brings them closer to the care receiver (Cohen, Colantonio & Vernich, 2002), providing a “rewarding opportunity to return the care they received in the past” (Watts & Teitelman, 2005, p.288). However, the negative effects of caregiving have been more widely documented throughout the literature (Cohen et al., 2002; Donovan & Corcoran, 2010). Caregivers have been described as “hidden patients” (Gitlin & Corcoran, 2005, p.9), who frequently experience burden related to restrictions in social and leisure occupations (Black et al., 2009; Egan et al., 2006). Dementia caregivers may experience increased burden compared with caregivers of people who do not have dementia (Lilly, Robinson, Holtzman & Bottorff, 2012; Pinquart & Sorensen, 2003). It has been suggested that the severity of the care receiver’s cognitive impairment and particularly the presence of behaviours that challenge may result in restricted participation in meaningful occupations for caregivers, and heightened caregiver burden (Contador, Fernandez-Calvo, Palenzuela, Migués & Ramos, 2012; Gitlin, 2012; Pinquart & Sorensen, 2004).

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1 The term “dementia caregivers” will be used throughout this paper to describe informal caregivers of persons with dementia.  
2 For the purpose of this paper, occupations are defined as “everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning...to life. Occupations include things people need to, want to, and are expected to do” (World Federation of Occupational Therapists [WFOT], 2006, p.2).

LITERATURE REVIEW

Participation in meaningful occupations has been deemed the overarching aim of the Occupational Therapy process (AOTA, 2008). There is a wide range of evidence for the relationship between occupational participation and health (Baum, 2003; Christiansen & Townsend, 2004; Creek & Hughes, 2008; Durocher, Gibson & Rappolt, 2013; Law, 2002; Jackson, Carlson, Mandel, Zemke & Clark, 1998). Occupational participation refers to engaging in personally and socially significant activities (Kielhofner, 2008). In Occupational Therapy, occupational participation is considered a “basic human need” (Polatajko et al., 2007, p.20) that is “vital to life” (Law, 2013, p. 49). Maintaining participation in meaningful occupations can enable caregivers to overcome challenges involved in dementia caregiving (Hasselkus & Murray, 2007). Unfortunately, caregivers often struggle to meet the demands of caregiving occupations (Cohn & Henry, 2009), which negatively affects their overall occupational performance (McGrath, Mueller, Brown, Teitelman & Watts, 2000).

Hasselkus and Murray (2007) described how dementia caregiving frequently results in “occupational disruption” (p.13), whereby caregivers’ occupational participation is restricted by care receivers’ needs. Occupational disruption is a short-term state, which can be resolved with adequate support (Christiansen & Townsend, 2004; Whiteford, 2000). However, if access to meaningful occupations is denied over a prolonged period of time by factors out of one’s control, occupational deprivation may occur (Christiansen & Townsend, 2004; Townsend & Polatajko, 2007). Since occupational participation facilitates social inclusion, occupational deprivation and social exclusion are interlinked (Whiteford, 2011; Whiteford & Hocking, 2012). Therefore, those providing care over a long period of time, without adequate support, risk becoming socially excluded and occupationally deprived.

Pierce (2003) emphasised the importance of occupational balance to health and well-being. Occupational balance is defined as an “individual’s perception of having the right amount of occupations and the right variation between occupations” (Wagman, Hakansson & Bjorklund, 2012, p.322). Occupational imbalance is defined by Anaby, Backman and Jarus (2010) as “a perceived disharmony, lack of fit or interference among occupations” (p.281). According to Stokes (2010), caregiving causes a change in the balance of occupations. Caregivers frequently sacrifice meaningful occupations, resulting in occupational imbalance (Egan et al., 2006; McGrath et al., 2000; Pickens, O’Reilly & Sharp, 2010). Family support, respite and assistance from other carers can enable informal caregivers to maintain occupational participation and prevent deprivation and imbalance from occurring (AOTA, 2008; McGrath et al., 2000).

Because caring for a relative with dementia impacts occupational participation, occupational therapists are uniquely qualified to provide interventions to optimise participation in meaningful occupations (Donovan & Corcoran, 2010; Hall & Skelton, 2012; Letts et al., 2011). Nonetheless, there is a lack of evidence of the effectiveness of Occupational Therapy for caregivers (Hall & Skelton, 2012; Letts et al., 2011). Bennett, Shand
and Liddle (2011) found that occupational therapists in Australia dedicated little time to caregiver interventions. In a review of the United Kingdom literature on Occupational Therapy for dementia caregivers, the only studies that robustly demonstrated improved caregiver outcomes were interventions delivered by clinical psychologists, nurses and drama/reminiscence specialists (Hall & Skelton, 2012). In contrast, recent research has provided evidence for the effectiveness of Occupational Therapy for people with dementia and their caregivers (Dooley & Hinojosa, 2004; Dopp et al., 2011; Gitlin, 2012; Graff et al., 2007; Letts et al., 2011). Graff et al. (2007) found that community Occupational Therapy intervention for people with dementia and their caregivers resulted in improved quality of life, health status and mood for clients and caregivers. Similarly, Dooley and Hinojosa (2004) found that an Occupational Therapy home assessment, together with individualised recommendations and one follow-up visit resulted in improved client and caregiver quality of life and decreased caregiver burden. In Ireland, Cadoo (2012) found that group-based psycho-educational training for dementia caregivers resulted in increased caregiver confidence and decreased burden. Unfortunately, dementia remains an overlooked and under-financed issue in Irish society (Cahill, O’Shea, & Pierce, 2012b). In 2010, the Irish government committed to developing and implementing a National Dementia Strategy (NDS) by 2013 (Cahill et al., 2012a). Although the NDS has yet to be implemented, the Alzheimer’s Society of Ireland’s (2012) submission to the NDS recommended training for dementia caregivers that was structured and tailored depending on the stage of the care receiver’s dementia. It suggested that training should empower caregivers by providing them with the education and skills required to effectively support the person with dementia.

Interventions in the community would not only provide benefits for people with dementia and their caregivers; research suggests that they may also be cost effective. Graff et al. (2008) found that community occupational therapy involving the use of cognitive and behavioural interventions, effective supervision, coping strategies and problem solving to promote independence and social participation for both caregiver and care receiver was “successful and cost-effective” (p. 1). Due to the variety of interventions in the literature, it is difficult to determine which interventions are most effective in terms of caregiver and care receiver outcomes and cost-effectiveness (Gitlin, 2012). Further research is warranted to explore how caregiving impacts individual caregivers’ occupational participation and to investigate factors which may enable or constrain participation (Hasselskis & Murray, 2007; Law, 2013). Specifically, the needs of dementia caregivers in Ireland have been neglected in the literature. Increased knowledge of how caregivers function in their daily lives would enhance therapists’ ability to improve occupational participation and quality of life for caregivers (Cohn & Henry, 2009; Egan et al., 2006; Watts & Teitelman, 2005). Based on these gaps in the literature, the following research question was proposed: What effect does caring for a relative with dementia have on an individual’s daily occupations and his/her ability to achieve perceived balanced occupational participation? The aims of the research were: i) to explore the daily occupations of dementia caregivers; ii) to investigate how their occupations have changed because of caregiving and the factors affecting change; iii) to consider caregivers’ emotional responses to these changes and their perceptions of their own occupational balance.

**RESEARCH DESIGN**

**Methodology**

A qualitative methodological approach was chosen for this exploratory research. Qualitative research affords the participant the position of expert, with the researcher assuming the role of learner, thus allowing honest, authentic views of participants to emerge (Wilding & Whiteford, 2005). The study was conducted using a phenomenological perspective. Phenomenology involves a direct study of human experience and allows a rich insight into the meaning of these experiences (Carpenter & Suto, 2008; Holloway, 2008; Polgar & Thomas, 2008; Richards & Morse, 2007).

**Ethical Considerations**

Ethical approval was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals, University College Cork, Ireland. All participants gave informed consent and signed consent forms before taking part in the study. Confidentiality was upheld throughout the research process. Names were changed and pseudonyms were used on written material, in discussions with the research supervisor and throughout this paper. Audiotapes and hard copies of information collected were stored in a locked cabinet. Information on the researcher’s computer was password-protected.

**Ethical Considerations**

Ethical approval was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals, University College Cork, Ireland. All participants gave informed consent. study.

**Participants**

Two purposefully selected participants (Dickerson, 2006) were sourced through a gatekeeper, the manager of a branch of the Carer’s Association. Snowball sampling (Barbour, 2008; Holloway, 2008) was used to access a third participant. Inclusion criteria were informal dementia caregivers, who considered themselves primary caregivers (Watts & Teitelman, 2005). Participants needed to be willing and able to participate in two semi-structured interviews, each lasting approximately 45 minutes. All participants met the inclusion criteria. The following table provides information about the three participants and their unique caregiving situations.
Research Methods
Two semi-structured interviews were conducted with each participant. Semi-structured interviews allow for the perceptions of significance to participants to be elicited, and facilitate the building of rapport (Taylor & Kielhofner, 2006). Through the semi-structured interviews, the researcher gained a rich insight into the unique perspectives of participants. The second interview, which took place one week after the first interview, afforded participants the chance to elaborate on issues mentioned in the first interview. By the second interview, the researcher had consolidated rapport and trust with the participants, who were more comfortable sharing personal experiences as a result.

Data Collection and Analysis
Before interviewing participants, questions were piloted on a caregiver known to the researcher. Following piloting, additional probes were added to the interview questions. Interviews with participants were audiotaped and transcribed verbatim. Data were analysed using thematic analysis. The researcher read and re-read transcripts to identify codes (Wilding & Whiteford, 2005). Codes were then re-coded by examining earlier codes and categorising by assigning labels to pieces of data with similar meanings (Carpenter & Suto, 2008; Green & Thorogood, 2009). Finally, major themes were developed (Carpenter & Suto, 2008).

Trustworthiness
Credibility of the research project was addressed by member checking (Schwandt, 2007). To enhance transferability, the researcher included descriptive information about participants (see table 1) (Creswell, 2007). Dependability was addressed by maintaining an audit trail of methods and procedures (Holloway, 2008) and a copy of all transcripts. Confirmability was achieved through the process of reflexivity (Green & Thorogood, 2009); the researcher kept a journal to reflect upon ways in which personal experiences and values could influence the study.

FINDINGS
The overarching theme, which organised the findings, was occupational participation. Occupational participation varied significantly among participants. Joanne was satisfied with her ability to participate in meaningful occupations, whereas Katie and Thomas reported restricted occupational participation. Occupational participation was enabled by support systems and constrained by the level of care required by the care receiver. The sub-themes which emerged were: i) “I wouldn’t have a clue”: Caregiving as a new occupation; ii) “I’m not doing anything; I can’t do anything”: Occupational deprivation and imbalance; iii) “I’d be lost without them”: Enabling factors; and iv) “So much care, so much attention”: Constraining factors. See figure one for diagram of theme and sub-themes.

Table 1: Participants’ demographic details

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Relationship to Care Receiver</th>
<th>Age of Care Receiver</th>
<th>Length of Time Caring</th>
<th>Level of Care Required by Care Receiver</th>
<th>Family and External Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thomas*</td>
<td>Husband</td>
<td>66</td>
<td>6 years</td>
<td>Requires assistance with all activities of daily living (ADLs) and environmental activity of daily living (EADLs); displays behaviours that challenge.</td>
<td>One daughter and her partner live with caregiver and care receiver; other daughters provide support; support from professional carers.</td>
</tr>
<tr>
<td>Joanne*</td>
<td>Daughter</td>
<td>61</td>
<td>91 years</td>
<td>Requires prompting with some ADLs; toilets independently; requires assistance with EADLs; no reported behaviours that challenge.</td>
<td>Joanne does not live with care receiver but she is the main carer. Her brother lives with care receiver (but works long hours); other brothers and sisters all provide support; support from professional carers; private carers also employed.</td>
</tr>
<tr>
<td>Katie*</td>
<td>Daughter</td>
<td>61</td>
<td>92 years</td>
<td>Requires assistance with all ADLs and EADLs; no reported behaviours that challenge.</td>
<td>Support from sons and daughters; care receiver attends day centre once weekly.</td>
</tr>
</tbody>
</table>

*Pseudonyms have been used to maintain confidentiality.

Figure 1:

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which were part of their caregiving role:

“She has to be gotten up, taken to the bathroom, washed...I dress her...give her her breakfast...put...make-up on her...But you get a little bit weary from it...cleaning, washing and it all has to be done” (Katie)

“I bring her in tea...then we...get her up, wash her and dress her...Being a carer now is very, very hard” (Thomas)

As well as providing direct care and supervision, caregiving involves choosing caregivers and organising care (AOTA, 2008). Selecting carers and organising care were new occupations in Joanne’s life:

“We met different girls...we gradually got the hours covered...I look after the timetables...I text the girls...to check that they’re free...I could get a text saying that...someone couldn’t come...Planning must be done but...we have it fine-tuned” (Joanne)

Not only did caregivers take on new occupations such as washing, dressing, feeding, and organising care, they also developed strategies for dealing with their relatives’ behaviours. One participant mentioned how her mother required “reassurance all the time”. Caregivers were constantly thinking of novel ways of doing things to facilitate continued occupational participation of the care receiver. They needed to be flexible when orchestrating occupations; they often had to change plans depending on the care receiver’s mood. For example, Joanne mentioned strategies she used to get her mother to come for a drive:

“Getting her to come round...if she doesn’t want to do something [or] go somewhere, I’ll say “look we’ll get in the car, we’ll go so far...and we can turn back”...then when she’s in the car it’s grand...just learning from experience” (Joanne)

Unfortunately, the strategies were not always successful. Thomas explained how he tried to find a way to get his wife to take her tablets, but she was unable to follow his instructions:

“What we have to go through to give her her tablets...I have to coax her to take them...she was chewing them and all her mouth was coated...[I say]...“look, swallow it off”...but she can’t swallow.” (Thomas)

“I’m not doing anything; I can’t do anything”

Occupational deprivation and imbalance

Two caregivers experienced occupational deprivation and imbalance resulting from caregiving. They had both been caring for a relative with dementia for six years and had sacrificed meaningful occupations because of restrictions arising from caregiving duties:

“I gave things up...We used to do a bit of bed and breakfast...I gave that up last year...another cut off...I would have been in the choir...just in general going out a bit more...I’m here all day...I couldn’t really...go anywhere” (Katie)

“As from all the activities I was doing...I’m gone down to doing nothing for myself...There are no activities...I can’t do anything...I can’t go anywhere.” (Thomas)

Caregiving also led to occupational imbalance for Thomas and Katie. A large proportion of their time was consumed by caregiving occupations, with little time for participation in other meaningful occupations, such as “going out and meeting people”:

“I have no balance...I don’t get any break from it...I’m on it 24/7...I try not to be out of here too long.” (Thomas)

“...a different balance back then...before caregiving...I would have been freer...to do things...the balance has shifted...to...now where I’m here with her quite a lot...my whole world is around this place” (Katie)

Both caregivers spoke of their emotional responses to occupational imbalance. The constant demands and the all-consuming nature of caregiving left them feeling strained and burdened:

“The six years is taking its toll...It’s constant...so it is difficult...it’s awful not to be able to...do as you want” (Katie)

“I’m trying to keep the good side out...I’m trying not to explode because I’m ready...but at the same time I can’t because of my wife” (Thomas)

Conversely, for Joanne, caregiving did not lead to occupational deprivation or imbalance. She briefly experienced occupational disruption when she first began caregiving. However, with support from family and professional carers, the disruption resolved. Joanne is now satisfied with her level of occupational participation:

“The biggest change would be having to spend more time with her...and to plan your life around that...I’m so used to it now [re-arranging plans]. If it comes, it comes and I’ll deal with it...I haven’t been cut off. I’m a member of the ICA [Irish Countrywoman’s Association]...and I go to Aqua Aerobics every Tuesday” (Joanne)

“I’d be lost without them”

Enabling factors

Occupational participation was enabled by support from family, professional carers and respite. Caregivers acknowledged that they were lucky to have family support and suggested that without support they would “be lost”:

“Without the family support, I...mightn’t feel as good about it...Support...makes it possible to take care of
ourselves...we're very lucky...None of us are overburdened.” (Joanne)

“Only for my daughters here I'd be lost...I'd be on my own. And I'd be wrecked altogether” (Thomas)

Two of the caregivers, Joanne and Thomas, had support from professional carers from the Health Service Executive, the Carer’s Association and the Alzheimer’s Society of Ireland. Support from professional carers gave Joanne peace of mind, knowing that her mother was always “in good hands”. Her family believed it was important to get as much help as possible. Therefore, they also hired private carers for their mother:

“finance...is very important...to pay for private carers...It’s great help...you definitely need all the support you can get.” (Joanne)

Unfortunately for Thomas, help from professional carers did not enable him to participate in meaningful occupations. Thomas felt that because his wife displayed behaviours that challenged, he could not leave her even when carers were present:

“The carer comes in...So I’m supposed to go off then but the wife don’t want me to go off so I’m caught with that...if she’s fighting them, they call me in and I persuade her...I’m still involved the whole time, no matter what” (Thomas)

Katie had no support from professional carers. She declined support because she felt she would have to clean up before other carers came in. However, she brought her mother to a day centre once a week, which provided respite and gave her a break from caregiving. Formal respite, whereby the caregiver was relieved from caregiving duties completely, enabled occupational participation for all caregivers. Examples of formal respite included the use of a day care centre and a nursing home. Caregivers reported having more freedom to engage in meaningful occupations when their relative was away from the home in formal respite:

“I love when she goes in [to respite care]...I really enjoy it....not having to get her up...not having to take her to bed...I just love the freedom...I can go to town...I actually don’t have to worry about anyone...I love that break...it’s relaxing” (Katie)

“I went over to England for a week last April and I really enjoyed it...it was a...proper break” (Thomas)

Informal respite was facilitated by caregivers’ families. For one participant, Joanne, family support was particularly effective in enabling occupational participation. Joanne’s brother took over caregiving duties for a few hours every week to facilitate her continued involvement in the ICA. At weekends her sister provided care, allowing her to “go to a match or just go visiting”.

“So much care, so much attention”: Constraining Factors

Factors that constrained occupational participation included the severity of the care receiver’s dementia and the resulting level of care required. The amount of care their relatives required limited Thomas’ and Katie’s ability to engage in meaningful occupations, such as meeting friends and participating in community groups:

“You have to be there [with her]...I would be very restricted...Mam [is] doubly incontinent as well, you know, there’s a lot to be done...just trying to get Mammy around...would be difficult...Sometimes it’s easier not to take her [to town]” (Katie)

“She needs 24/7 care...I wouldn’t like to leave her” (Thomas)

In addition to her physical care needs, Thomas’ wife displayed behaviours that challenged, making caregiving more difficult and increasing caregiver burden. Thomas found dealing with these behaviours exhausting and distressing:

“Helping getting her into bed...she’d hit out and kick out and call me...all the names under the sun...I’m either committing incest or I’m a dirty old man. This is...what I’m going through, what I have to deal with.” (Thomas)

In contrast, Joanne’s mother did not present with behaviours that challenge and was still able to toilet and mobilise independently. Therefore Joanne could take her on outings, maintaining occupational engagement and social participation:

“She’s able to...go to the toilet herself...which is great...[She is] fairly mobile...In the summertime we go for a drive, she loves that...in the winter...my brother has a pub [public house]...we sit there and she’ll sit there so happy” (Joanne)

DISCUSSION

Occupational Therapy is based on the assumption that participation in meaningful occupations positively influences health (Baum, 2003; Christiansen & Townsend, 2004; Creek & Hughes, 2008; Durocher et al., 2013; Law, 2002). Facilitating participation in meaningful occupations has been the essence of Occupational Therapy since the founding of the profession (Baum, 2003; Law, 2002). Occupational participation also emerged as the primary theme from interviews with caregivers in this study. The following four subthemes were identified: i) “I wouldn't have a clue”: Caregiving as a new occupation; ii) “I'm not doing anything; I can't do anything: Occupational deprivation and imbalance; iii) “I'd be lost without them”: Enabling factors; and iv) “So much care, so much attention”: Constraining factors.

Participants in this study had taken on many new caregiving occupations such as assisting the care receiver with washing, dressing and feeding, as well as organising care. Caregiving was described not only as a new occupation, but as a difficult occupation that was...
unfamiliar, daunting, and overwhelming. Similarly, previous studies have described caregiving as an intense, challenging, multifaceted occupation (Egan et al., 2006; Thines & Padilla, 2011). Participants in this study reported that initially they didn’t “have a clue” how to complete caregiving tasks and were “learning from experience”. They had developed new strategies for dealing with care receivers’ behaviours and “getting [them] to come round”. Likewise, Josephsson, Backman, Nygard and Borell (2000) found that dementia caregivers used diverse approaches to manage problems they encountered while caregiving. The findings of this study suggest that dementia caregiving differs from caring for someone with a physical disability in that it involves more than just carrying out physical care tasks; it also involves coaxing and reassuring the care receiver and planning new ways of doing things. Therefore, dementia caregiving is an incessantly demanding and emotionally challenging experience (Gitlin & Corcoran, 2005; Papastavrou et al., 2011). Not surprisingly, it has been reported that dementia caregivers are more vulnerable to burden than those caring for a person without dementia (Pinquart & Sorensen, 2003, 2004) and thus may require additional support from occupational therapists and other healthcare professionals.

The findings suggest that caregiving does not necessarily always result in negative outcomes for caregivers (Cohen et al., 2002; Lopez et al., 2005), provided meaningful activities are not restricted (Pinquart & Sorensen, 2004). However, caregivers who are overwhelmed by the demands of caregiving occupations may experience difficulty participating in leisure and social occupations (Cohn & Henry, 2009; Pinquart & Sorensen, 2003). This was the case for two of the participants in this study, who were forced to discontinue involvement in enjoyable occupations, such as choir practice and community projects because of caregiving. Consequently, both caregivers felt that they lacked balance in their lives between the occupations they wanted to do (meeting friends, etc.) and those they had to do (caregiving). They reported feeling socially isolated and “cut away from the world”. They felt it was “harder to get back in” to social circles when they had been absent for so long as a result of caregiving duties. They were left feeling “weary”, “fed up” and “frustrated” because of the “constant” demands of caregiving. Other studies have also suggested that caregivers are at risk of experiencing occupational imbalance and have emphasised the importance of caregivers remaining involved in hobbies and receiving social support (Donovan & Corcoran, 2010; Hasselkuss & Murray, 2007; Lee, Czaja & Schulz, 2010; Pickens et al., 2010).

The findings indicate that the level of care required by the care receiver restricted caregivers’ occupational participation. Participants caring for a relative who required assistance with all ADLs had limited opportunities to engage in occupations unrelated to caregiving. For example, Katie reported that she did not like to take her mother to town because of her limited mobility and incontinence. Conversely, in Joanne’s case, her mother was independently mobile and continent; Joanne could take her to the public house, therefore maintaining occupational participation and social inclusion for herself and her mother. These findings are consistent with reports by Pinquart and Sorensen (2004) that when caring for a more impaired person with dementia, participation in pleasurable occupations is restricted. Similarly, Gitlin and Corcoran (2005) stated that as dementia progresses, and care receivers become more dependent on caregivers, the social networks of caregivers often diminish.

Occupational participation for one of the caregivers, Thomas, was further constrained because his wife displayed behaviours that were challenging. Numerous studies have supported this finding, and have suggested that care receivers displaying behaviours that challenge could lead to caregiver depression and burden (Contador et al., 2012; Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourzi, 2007; Pinquart & Sorensen, 2004). Indeed, Thomas reported that in trying to manage his wife’s behaviours, he was going through his “own hell, [his] own agony”. He could not relax and did not want to leave his wife even when professional caregivers were present. Watts and Teitelman (2005) found that caregivers often worry that the care receiver may be distressed by their absence and that others may not be able to provide care as well as they could. This was true in Thomas’ case; he felt he needed to be present in case the professional carers could not manage his wife’s behaviours and required him to intervene. In contrast, Joanne’s mother did not display behaviours that challenge and therefore, Joanne felt comfortable leaving her mother with professional caregivers, while she engaged in other activities. This reflects Gitlin’s (2012) assertion that managing behaviours that challenge is “one of the most demanding and difficult aspects of care” (p.894).

Consistent with research by McGrath et al. (2000), formal and informal respite enabled caregivers in this study to participate in meaningful occupations such as travelling and shopping. Family members provided emotional support and facilitated informal respite by assisting with caregiving duties and encouraging caregivers to take a break. All participants also had access to formal respite services, which gave them “freedom” to engage in occupations outside of caregiving. Watts and Teitelman (2005) found that many caregivers experienced pressure to complete as many tasks as possible before respite ended, and therefore did not achieve a restorative break during respite. However, caregivers in this study seemed to have a different attitude towards respite. They used respite to relax, to engage in leisure occupations and to complete tasks that they enjoyed (such as gardening) but had postponed due to their caregiving commitments. Occupational therapists can enable caregivers to find opportunities for informal respite throughout their daily lives, helping them to increase participation in meaningful occupations (McGrath et al., 2000; Watts & Teitelman, 2005).

CONCLUSION

Implications for Occupational Therapy practice

The findings of this study suggest that caring for a relative with dementia has an impact on caregivers’ occupational
Therapists could advocate for caregivers’ needs, for example, by informing them about local support groups, where they may increase their social contact and receive emotional support (Droes, Meiland & van Tilburg, 2006; Thinnes & Padilla, 2011). Occupational therapists can also help caregivers to coordinate others in caregiving duties (Gitlin, 2012; Gitlin & Corcoran, 2005). Occupational therapists should encourage caregivers to utilise opportunities for breaks from caregiving (Donovan & Corcoran, 2010; Rosa et al., 2010; Watts & Teitelman, 2005), which would enable continued occupational participation and social inclusion.

Limitations of the study and recommendations for further research
This study describes the experiences of three Irish dementia caregivers living in the South/South-East region of Ireland. The sample may not be representative of all informal dementia caregivers in Ireland. Further research should examine the occupational lives of caregivers from wider geographic locations and more ethnically diverse populations. All caregivers in this study were aged between 61 and 66 and were not involved in childrearing or in work outside the home. Further research with younger caregivers, who are engaged in the workforce and are involved in childrearing, could explore how caregiving impacts these occupations. Research comparing the occupational participation issues of spousal caregivers versus non-spousal caregivers would also provide useful insights into caregivers’ differing occupational needs. Specific criteria for inclusion would be useful to elicit information from future studies. Finally, future researchers should investigate the effectiveness of various caregiver interventions in enabling occupational participation. In addition, the cost-effectiveness of such interventions in an Irish context could be examined.

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KNOWLEDGE AND ATTITUDES OF IRISH OCCUPATIONAL THERAPISTS TOWARDS RECOVERY.

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ABSTRACT

The Irish policy document, ‘A Vision for Change’ has stipulated that the recovery ethos should inform all levels of mental health care in Ireland. A cross-sectional study was used to explore the extent to which occupational therapists in Ireland were recovery focused. Results found that participants had the highest level of knowledge in terms of positive roles and peers in facilitating the recovery focus. The lowest level of knowledge was found with regards recovery and symptoms of mental illness coexisting as well as the role of non traditional interventions in the recovery process. The findings emphasize the strengths of occupational therapists in the implementation of vision for change for mental health consumers as well as areas in which further development is needed.

KEYWORDS

Recovery, Occupational Therapy, Mental Health

INTRODUCTION

The Mental Health Strategy ‘A Vision for Change’ states that a recovery orientation should inform every aspect of service delivery in Irish Mental Health Services in Ireland (Department of Health and Children, 2006). However, seven years on, evidence is suggesting that services are still not practicing recovery focused care. Occupational therapists are prominent providers of this care and links have been made between the philosophical underpinnings of the profession and recovery (Rebeiro-Gruhl, 2005). The profession is therefore in a position to support the recovery movement in practice. Cleary and Dowling (2009) found an ambiguity amongst health professionals in general in terms of their knowledge and attitudes towards recovery in Irish health services. This study seeks to investigate the knowledge and attitudes of occupational therapists specifically to determine the extent to which this group, whose training has a strong basis in recovery, is recovery focused.

What is Recovery?

Since it first appeared in the literature (Anthony, 1993; Deegan, 1998), the concept of recovery has been implemented at a policy level both nationally and internationally. Although ‘recovery’ is a prominent concept in mental health services, there is little consensus in the literature with regards to a succinct definition. However, a number of key concepts have become linked with recovery, illustrating how this philosophy differs from the traditional view of mental illness. These include the view of the concept of cure, the experience of mental illness and relapse, as well as the shift in power from the professional to the service user.

The traditional focus on mental health services was on the reduction of symptoms and the associated deficits and dysfunctions. Success in health services was therefore measured on the extent to which the service was able to achieve this (Repper & Perkins, 2003). Deegan (1993)
suggestions the differing focus of recovery away from curing symptoms to the ability of a person to live a meaningful and valuable life despite the presence of symptoms. Although the concept of “cure” from mental illness is not always attainable, the possibility of recovering a meaningful and valued life is. Recovery therefore encompasses the hope that re-establishing this meaning and value is achievable.

Anthony (1993) describes recovery as a journey as opposed to a destination, focusing on the possibilities for personal growth in the face of mental illness. Recovery is therefore not a linear process but one where setbacks take place and personal growth occurs as a result. Relapse is therefore reframed from a “failure” focus in traditional mental health services to one of opportunity, where learning can occur to enable a person move beyond their limitations by identifying the support and adjustments they need to pursue ambitions (Repper & Perkins, 2003).

In addition, traditional mental health services took a paternalistic approach where the professional was considered the leader in the consumers’ care. Recovery focused services differ in their emphasis with regards to competence, viewing the service user as the expert in their own care, rather than a passive recipient of services (Anthony, 1993). Although mental health services provide support and assistance for those experiencing mental illness, the recovery movement highlights the added sources of meaning for a person outside of the mental health services e.g. work, peer support groups and leisure pursuits. Drawing from the Social Inclusion Movement, recovery promotes access to the opportunities of ordinary citizens for those experiencing mental illness and the resources beyond mental health services that enable that to happen.

**Impact of recovery for consumers**

Since the emergence of the recovery movement in the 1980s there is documented evidence of the benefits of a recovery philosophy for consumers of mental health services. Consumers report valuing a recovery oriented approach (Corrigan et al., 2006; Mancini, Hardiman, & Lawon, 2005) and there has been increasing evidence that supports the benefits of recovery based practice for consumer outcomes. Chiba, Kawakami and Miyamoto (2011) found a strong, positive correlation between recovery and benefit finding which includes increased coping strategies amongst persons with chronic mental illness in Japan. A study by Hasson-Ohayon, Roe & Kravetz (2007) concluded that participants of an illness management and recovery programme showed significant improvement in knowledge about their illness and progress towards their goals when compared to those receiving usual care. Similarly, Levitt and colleagues conducted a randomised controlled trial which concluded that an illness self-management and recovery programme improved personal management and functional outcomes for consumers above the control group (Levitt et al., 2009).

**Impact of staff on implementation of recovery**

The Mental Health Commission (MHC) (2008) identifies staff within the mental health organisation as a key contributor in recovery in practice. This is supported by several studies that show that specific staff skills and behaviour contribute to the process of recovery, including effective communication, providing hope, appropriate self-disclosure and a mutual, equal and respectful partnership in treatment (Crowe, Deane, Oades, Caputi & Morland 2006; Hugo, 2001; Ranz & Mancini, 2008; Young, McCormick, & Vitaliano, 2002). Oades, Crowe, & Nguyen (2009) concluded that provider hope transfers to consumers, therefore the knowledge and attitudes practitioners have for recovery could be a significant influencing factor in the extent to which recovery is transferred into practice. In addition, Young et al. (2005) concluded that providers lack knowledge about the concept and this may be a critical barrier to implementing recovery orientated services.

Cleary and Dowling (2009) examined the knowledge and attitudes of mental health professionals to recovery in an Irish context. The findings indicate that the concept is viewed positively as a philosophy of care for delivering mental health services amongst participants. Respondents were less comfortable however in encouraging healthy risk-taking although this and hope are seen as integral to the recovery process (Repper & Perkins, 2003). There was an acknowledgement of the need for information, training and education for both professionals and services users in order to transfer the concept into practice. Despite this need however, it is less certain how to ensure that staff members actually demonstrate the competencies that support recovery and whether it is possible to train these skills (Hugo, 2001).

**Recovery in Ireland**

Recognising the benefits of the recovery ethos and the shift in the focus on mental health care from institutionalisation to recovery, health policy throughout the world sought to move it beyond an aspiration (Borg & Kristiansen, 2004; Rebeiro-Gruhl, 2005). In Ireland the advent of the movement came with the publication of the mental health policy document ‘A Vision for Change’ (DOHC, 2006).

This policy document was developed following a consultative process with consumers and other stakeholders, highlighting that recovery should inform every level of mental health service provision. It called for “person-centred treatment” and stipulated the need for active partnerships between consumers, carers and mental health professionals. The focus was not only on the equal partnership of consumers, but also on active engagement at a national advisory level.

Since the launch of this document, the success of the Health Service Executive (HSE) in implementing the recommendations has been questionable. Although a number of successes have been acknowledged including the establishment of the National Service Users Executive...
Occupational Therapy and Recovery

Occupational therapists strive to enhance the participation of people with the wider community, enabling individuals to prevent and overcome obstacles, secure wellbeing, and improve the quality of their lives (American Occupational Therapy Association, 2007). A number of authors have drawn links between this philosophy and that of recovery, and have encouraged occupational therapists to utilise recovery-based approaches in their work (Kelly, Lamont, & Brunero, 2010; Lloyd, Waghorn, & Williams, 2008; Rebeiro-Gruhl, 2005). A consumer collaborating on a report on the future of occupational therapy in mental health services in the UK felt that occupational therapists had a major role to play in the process of recovery (Council of Occupational Therapists, 2008). In addition, Rebeiro-Gruhl (2005) argued that by virtue of professional beliefs and assumptions, occupational therapists are uniquely positioned to assume a leadership role in the area of recovery-related research and practice. Tools such as the Canadian Occupational Performance Measure (COPM) (Law et al, 2004) have been identified as a platform for capturing the complex constructs that comprise recovery for an individual (Kirsh & Cockburn, 2009) thus implementing recovery in intervention planning. Although a recent systematic review indicated that there has been little research to date on the effectiveness of the recovery approach as practiced by occupational therapists, there is moderate to strong evidence for the effectiveness of therapy focused on the components of recovery e.g. community re-integration, social skills training, supported employment and supported education (Gibson, DaAmico, Jaffe, & Arbesman, 2011).

There is a recognised shift at a policy level for a recovery focused care and occupational therapists have been identified as prominent members of the multidisciplinary team in implementing the recovery philosophy in mental health services. Knowledge and attitudes of staff to recovery has been linked with the transfer of this ethos to practice. Although the Irish mental health clinicians’ knowledge and attitudes to recovery has been investigated by Cleary and Dowling (2009), occupational therapists accounted for only 4% of the study population of mental health workers. This study sought to complete a fuller investigation of the research question for an occupational therapy population.

METHOD

A cross-sectional study was carried out using the Recovery Knowledge Inventory (RKI) (Bedregal, O’Connell, & Davidson, 2006) to measure the knowledge and attitudes of occupational therapists working in mental health settings and in primary care settings. The following research questions were addressed:

- What are the current knowledge levels and attitudes of occupational therapists in Ireland to recovery?
- Are there differences in the knowledge and attitudes of occupational therapists towards recovery related to their employment grade, tenure, age, geographical location or sex?
- Does reading or training influence knowledge or attitudes to recovery?

Research Measure

In addition to basic demographic data, the Recovery Knowledge Inventory (RKI) (Bedregal et al., 2006) was used with permission of the author as the survey instrument for this study. This 20 item inventory has been used in two studies to examine the knowledge and attitudes of clinicians towards recovery (Cleary & Dowling, 2009; Meehan & Glover, 2009). The content validity, internal consistency reliability and internal structure of this instrument was examined and developed in consultation with all stakeholders (Bedregal et al., 2006), resulting in the 20-item inventory used for the current study. The psychometric properties of the RKI for a non-American population was established by Wilrycx, Croon, van den Broek & van Nieuwenhuizen (2012). The RKI includes items which quantify service providers’ knowledge and attitudes in the four key components of recovery:

- roles and responsibilities in recovery – 7 items regarding risk-taking, decision-making and the various roles and responsibilities of individuals involved in the recovery process, including people in recovery, and service providers
- non-linearity of the recovery process – 6 items regarding the non-linear nature of the recovery process, including the role of symptom management
- the roles of self-definition and peers (consumers) in recovery – 5 items regarding how the individual in recovery defines their own identity, their wider occupational lives including participation in leisure and work, and the role of peer support in recovery
- expectations regarding recovery – 2 items regarding the expectation of recovery.

Study participants

Occupational therapists working in community mental health settings and primary care settings working with a diverse client group were invited to participate in this
study. A snowball sampling technique was used to attract participants to this study. This method was selected to take advantage of the networks between identified respondents, and can expand the set of potential contacts (Thomson, 1997). Thirty-two Occupational Therapy managers in primary care and mental health across the four Health Service Executive (HSE) regions in Ireland acted as gatekeepers in this study and were strongly encouraged to forward this survey to all occupational therapists within their teams. Managers were reminded about the study twice in the following weeks, in an effort to improve the response rate.

Study Design
The RKI survey was electronically distributed to Occupational Therapy Managers, and forwarded to Occupational Therapy staff working in mental health and primary care teams. The use of electronic surveys has been found to be a useful method for accessing targeted populations such as professional groups, and for producing results which are in a format suitable for analysis (Shannon, Johnson, Searcy, & Lott, 2002).

Data Analysis
Data analysis was performed using Statistical Package for the Social Sciences (SPSS) version 20.0. Tests were two tailed and assumed a cut off of P<0.05 for statistical significance.

Ethical issues
The study proposal was reviewed by the Department of Occupational Therapy ethics committee at the National University of Ireland Galway and approval obtained.

RESULTS
30 participants responded to this survey, 26 of which were complete and returned for analysis. Table 1 illustrates the demographic profile of the participants. 81% of participants were female and under 50 years of age. Over 50% were of senior grade with 65% of the sample representing community mental health therapists. The majority of participants were from the west of the country with less than 5 years’ experience as an occupational therapist.

What are the current knowledge levels and attitudes of occupational therapists in Ireland to recovery?

The highest level of knowledge and attitudes was demonstrated on the component ‘role of self-definition and peers (consumers) in recovery’. This indicates that participants were most knowledgeable and had more positive attitudes with regards to the need for a consumer in recovery to develop a positive identity and the importance of fellow consumers in this process. Participants obtained a similar score in ‘roles and responsibilities in recovery’ indicating a positive attitude towards consumers deciding on their own treatment goals. Participants scored lower in ‘expectations regarding recovery’ indicating that they were more unsure about how to develop hopeful yet realistic expectations of recovery with their participants. The lowest mean score was found on the component ‘non-linearity of recovery’. This indicates less of an understanding of the recovery process, including the idea that recovery can progress despite the on-going presence of symptoms, and that consumers can recover using non-traditional treatments and settings.

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Non-parametric statistical tests were used to analyse the data and address the remaining research questions. With a small sample size, no randomisation occurred in the sampling.

Are there differences in the knowledge and attitudes of occupational therapists towards recovery related to their employment grade, qualification, sex, age, geographical location or tenure?

Results would indicate that employment grade, qualification, sex, age or tenure did not significantly influence recovery scores, however geographical location did. A Kruskal-Wallis test found no statistical significant
differences between staff grades or individuals with different qualifications while a Mann-Whitney test confirmed no significant differences between male and female respondents. Similarly a Spearman’s correlation coefficient test confirmed no difference in scores of participants in terms of age or length of time working as a therapist. A Kruskal-Wallis test did find a statistically significant difference between therapists in different HSE areas on their knowledge and attitudes towards the concept of the ‘non-linearity of recovery’ H(2) = 8.923. Post-hoc analysis demonstrated that there was a statistically significant difference between therapists in the HSE West and HSE Dublin/Mid Leinster, with those in the HSE West having significantly more positive levels of knowledge and attitudes in this component.

Does reading or training influence knowledge or attitudes to recovery?

Having read information about Recovery did not appear to result in any significant difference in knowledge and attitudes towards Recovery. However, receiving training on Recovery did result in a significant difference in recovery scores. A Mann-Whitney U test found statistically significant differences between those who had received training and those who had not on their scores on ‘Recovery Expectations’, ‘Non-Linearity of Recovery’ and the ‘Role of Self-Definition and Peers in Recovery’.

DISCUSSION

The findings from this study suggest that occupational therapists view recovery positively in delivering mental health care in Ireland with high mean scores in all domains on the Recovery Knowledge Inventory (RKI) similar to that of previous studies. The highest level of knowledge amongst participants was in the domain of ‘role of self-definition and peers in recovery’ (mean 4.08). This domain also received the highest scores in a study of 169 staff during the psychometric development of the RKI (mean 4.15)(Bedregal et al., 2006). This illustrates an appreciation among mental health staff for the need for a strong positive identity and the importance of peers in the recovery process.

Participants of this study also scored highest in the domain of ‘roles and responsibilities in recovery’ (mean 4.02). The concept of the client assuming roles beyond patient or addict is a prominent feature in occupational therapy theory and practice (Creek, 2008). Turner-Crowson and Wallcraft (2002) found that receiving a psychiatric label had a negative impact amongst the participants of their study in the quest to lead a worthwhile and enjoyable life. Moving beyond the notion of labels to focus on positive roles is promoted by Bedregal and colleagues (2006) as integral to the recovery process. Cleary and Dowling (2009) found that there was a statistically significant difference in mean scores on this domain between non-nursing staff (mean 4.00) and nursing staff (mean 3.68). Assuming the majority of this non-nursing staff were allied health professionals, this result would be consistent with the findings of this study on the specific allied health population of occupational therapists.

The lowest scores were found in the domain of ‘non-linearity of the recovery process’ (mean 3.08). This encompasses the concept that a person does not necessarily need to be free from illness and symptoms to be in recovery (Bedregal et al., 2006). This domain was also the lowest scoring in the study by Bedregal et al. (2006), where the mean score among staff on this domain was 2.78. While the occupational therapists surveyed in the current study scored higher than the mental health staff in Bedregal et al. (2006), it would suggest a greater understanding is still needed amongst mental health workers in recognising that recovery focused care does not seek to eliminate symptoms but facilitate consumers to navigate and manage them. Clarke et al. (2009) found that when symptoms are perceived as less distressing, consumers are better able to progress toward their case-management goals. This would suggest that therapists’ skills in enabling consumers to understand and manage these symptoms can facilitate them in continuing to goal set which is a key intervention tool used by occupational therapists in mental health care.

Findings also revealed that those employed in the west of the country had a more favourable attitude to the component of non-linearity of recovery. Gough and Trehy (2011) found that a Dublin based occupational therapy population felt that their service reflected recovery principles attitudinally where consumers were encouraged towards life goals and that intervention is service-user led. However, they felt that the service was not so recovery-oriented in its provision of a diversity of services, or the active involvement of the service-user on advisory or management boards. More research may be required to determine why there was a difference in these populations from a national perspective.

This study concluded that receiving training on recovery resulted in a significant difference in recovery scores. This supports the findings of Tsai, Salyers and McGuire (2011) who conclude that recovery training is positively related to staff recovery attitudes and agency practices. Meehan and Glover (2009) also found that knowledge and attitudes of staff were significantly improved on the Recovery Knowledge Inventory, six months post-training. However Peebles et al. (2009) concluded that this does not necessarily translate into changes in practice. Meehan et al. (2008) labels the assumption of a recovery focused service by virtue of the changes in clinicians values as naive. For example challenges can occur for individuals with long standing mental illness who may see recovery as an indicator of failure on their part. Similarly, when a consumer seeks to exercise their self determination by choosing to cease medication when it may be at odds with the research evidence and experience available to the clinician. The clinician can find themselves being required to work in a risk adverse fashion when the wider range of accountabilities expected of them is acknowledged. The level of knowledge and subsequent behaviours in practice which a clinician needs to actively utilise recovery in practice is significant. Similarly, they suggest that the operational level of the recovery ethos requires broad consultation and reflection at an organisational level before a wholistic effective recovery ethos can be achieved. Further research is
needed to examine the extent to which knowledge and attitudes transfer to behaviours in practice as well as the organisational factors that are required to result in a truly recovery focused service.

CONCLUSION/RECOMMENDATIONS

This study has highlighted the strengths of occupational therapists in the implementation of the current mental health strategy in Ireland. It outlines how occupational therapists are using concepts of recovery in practice including moving beyond labels with a focus on more positive roles for consumers. This also recognises the areas in which therapists may need further assistance in facilitating the move towards a recovery focused mental health sector. These include the concept that symptoms can be present in recovery and the value of non traditional interventions in mental health care. Recognising these gaps in therapists’ knowledge and attitudes towards recovery may enable services to target education to address these training needs.

LIMITATIONS

This study had a small sample size, therefore is limited in the extent to which it can make conclusions with regards the population as a whole. Although an electronic survey was cited as being an effective strategy, the use of this as a sole method of data collection did have its limitations as found in previous studies (Leece et al., 2004; Sprague et al., 2009). A more individualised approach may have resulted in a larger sample size including the use of various data collection methods to suit the needs of therapists without individual computers, such as hard copy surveys and the option of posting responses back to the research team.

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EXPLORING THE PROFESSIONAL EXPERIENCES OF OCCUPATIONAL THERAPISTS WHO STARTED WORKING IN THE REPUBLIC OF IRELAND IN THE 1970S.

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KEYWORDS
Occupational Therapy, history, Ireland

Background: Occupational Therapy associations and scholars are increasingly encouraging historical research in order to better understand, support and develop the profession. However, there is currently little published material on the history of Occupational Therapy in the Republic of Ireland.

Objectives: This study aims to explore the professional experiences of occupational therapists who started working in the Republic of Ireland in the 1970s. It also aims to contribute to national and international literature on the history of the profession.

Methods: A qualitative methodology was used involving seven in-depth interviews with occupational therapists who began working in the 1970s. Findings were analysed thematically.

Results: Findings highlight the experiences, challenges, rewards and contributions of occupational therapists who graduated in the 1970s. Themes include developing services; professional recognition; and professional and personal development.

Conclusions: It is hoped these findings will contribute to greater understanding of the early development of professional Occupational Therapy in Ireland.

INTRODUCTION

Health professions around the world are making increasing efforts to explore, record and promote their histories (Duffin, 2010; Molke, 2009; Oakley, 2005). Indeed the history of nursing and medicine is particularly well documented, both in Ireland and abroad (D’Antonio, 2010; Fealy, 2005; O’Brien, 1984; Porter, 1996). These professions are motivated to record their histories in order to better understand and critique their profession. They also aim to learn from the achievements and struggles of others, to contribute to professional identity, and to reflect on the value of their profession’s contribution to society (Canadian Nurses Association, 2007; Trentham, 2011).

Occupational Therapy is no exception in encouraging the active investigation of its history (Hall, 2013). However, what is exceptional is the absence of any formal record of the history of Occupational Therapy in Ireland. In fact, to date only a small collection of historical material exists including published interviews with pioneering occupational therapists, obituaries/appreciations and unpublished MSc theses (Boland & Boyle, 1997; Butler & Ryan, 2004; Flynn 2011; Lenihan, 2010; O’Rourke, 2005; Patterson, 2004; Prior, 2006; Ring, 2013). Professionally qualified occupational therapists started working in Ireland after World War Two; the first
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professional Occupational Therapy educational programme was established at St. Joseph’s College of Occupational Therapy in Dun Laoghaire, Co. Dublin in 1963. The Association of Occupational Therapists in Ireland was admitted to the World Federation of Occupational Therapy in 1970 (Irish Times, 1970). The profession developed further during the 1970s, with occupational therapists expanding services in rehabilitation, intellectual disability, vocational training and mental health (Lynch, 2014). In 1986, the first Irish degree programme in Occupational Therapy commenced at Trinity College Dublin, replacing the diploma programme offered at St. Joseph’s College of Occupational Therapy.

The University of Limerick’s (UL) History of Occupational Therapy Project aims to develop deeper understandings of the history of Occupational Therapy in Ireland. This study, which forms part of the wider work being undertaken at UL asks ‘what were the professional experiences of occupational therapists who started working in Ireland in the 1970s?’ As the Association of Occupational Therapists in Ireland (AOTI) prepares to celebrate its 50th anniversary in 2015 and the profession moves towards state registration it is hoped that the work being undertaken at UL will help trigger critical reflection on the development of the discipline in Ireland.

**Study aims:**
To explore and record the professional experiences of occupational therapists who started working in the Republic of Ireland in the 1970s.

To identify the key challenges and rewards related to their experiences.

To contribute to understandings of the development of Occupational Therapy in Ireland and internationally.

**METHODS**

As the purpose of this study was to understand the professional experiences, views and insights of occupational therapists who worked in Ireland a qualitative approach was most appropriate. The chosen research method was semi-structured interviews which gathered information about occupational therapists’ professional experiences, opinions and insights (Mason, 2002; Pontin, 2000). This method provided a framework with which to structure and compare interviews, ensuring that key issues were addressed, while also allowing for new issues to be discussed with each participant (Hammell, Carpenter & Dyck, 2000; Porter, 2000). Interviews lasted between thirty and ninety minutes (averaging sixty minutes) and were framed in clear and open language (Hammell et al., 2000). Interview guides were developed based on issues that arose from the literature review. Examples of questions that were asked included: ‘Why did you decide to become an occupational therapist? What are the key professional developments that you have witnessed or experienced? How would you rate your satisfaction with your working life? What was your biggest professional challenge? ’ Interviews were piloted and then conducted at a time and place most suitable for participants.

**Data collection and analysis**

Participants were recruited via convenience sampling and snowballing (Hammell et al., 2000). The first participant was recruited through a personal network while all further interviewees were recruited by asking participants to recommend friends and colleagues who would be interested in taking part. Interviews were then conducted at a time and place convenient for participants and recorded with a digital recorder. Field notes were used to record data, impressions and thoughts about the interview process and outcomes (Pontin, 2000). The interviews were subsequently transcribed verbatim and Analysed, coded, and synthesised using data analysis software, NVivo. A process of thematic analysis was then used, which is a method for identifying, analysing and reporting patterns (themes) by searching across a data set to identify repeated patterns of meaning (Braun & Clark, 2006). This process involved becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes and producing results (Braun & Clark, 2006). Findings were then connected back to the original literature and illustrative quotes were indexed and used to emphasise points from core categories and to demonstrate how meaning was expressed in the respondents’ own words rather than those of the researcher, thereby enhancing credibility (Greenhalgh, 2006; Hammell et al., 2000).

Indeed, addressing credibility, transferability, dependability and confirmability are essential strategies for ensuring trustworthiness in qualitative research projects and this was ensured throughout the project (Hammell et al., 2000; Letts et al., 2007). For example, credibility was further enhanced by debriefing regularly with the second author to ensure faithful interpretation and recording of results; transferability was ensured by making connections to existing literature to highlight similarities and contrasts; dependability was addressed by recording analytical decisions in field notes and reflective journals, while confirmability and faithful documentation of results was assured by donating the raw data, such as the audio recordings and transcripts, to the History of Occupational Therapy in Ireland Project at the University of Limerick. Lastly, ethical approval was obtained from the University of Limerick Education and Health Science (EHS) Research Ethics Committee.

**RESULTS**

Participants Seven occupational therapists agreed to participate in the study. They were all Irish female graduates of St. Joseph’s College of Occupational Therapy. Interviewees worked in a wide variety of services including community care, psychiatric hospitals, paediatric services, community mental health teams, regional hospitals, and intellectual disability services. They also held a range of positions and responsibilities including senior therapist, chief executive, Occupational Therapy manager and local health manager. Four participants were retired while three
were still working and they lived in four different regions of the Republic of Ireland. During the analysis of the interview data three primary themes emerged: developing services; the problem of professional recognition; and professional and personal development. To illustrate the themes, direct quotes made by the participants are included. Pseudonyms are used to help maintain confidentiality.

**Developing services**

One of the most prominent findings from the study was participants’ descriptions of the challenges they faced at the beginning of their professional careers. In most instances participants began work as the first and only occupational therapist in a service, which various participants described as isolating, intimidating, stressful, or even liberating in terms of the autonomy it granted. There, they were expected to establish services from scratch with no support, mentoring, supervision, training, structure, or guidance. They had limited resources, large caseloads or catchment areas, and encountered very poor understanding among fellow staff and Health Boards about what they were trying to do. Many also recalled the constant need to fight their case and justify their role and most said they would strongly advise new graduates to seek positions that provided effective support and mentoring. In addition, one participant lamented what she called ‘a lot of wasted years’ in her early career where she felt she could have done so much more if she had had appropriate support and resources. This ‘waste’ affected clients, services, and levels of job satisfaction and appropriate support and resources. This ‘waste’ affected clients, services, and levels of job satisfaction and.

“There was no sort of set programmes that this is what needs to be done, it was very much just get on and do it which looking back I mean it was ridiculous for somebody straight out of college with no experience to go to a place where no one had a clue what you were going to do.” (Frances)

“I don’t believe that at that stage the Health Board had any conception of what occupational therapists actually did, which gave you great freedom but at the same time really left you out there very isolated and it was quite intimidating.” (Myra)

“In some ways I feel, wasn’t it a pity I didn’t get the early mentoring and training...because in a way I look back with regret at a lot of wasted years, but I did the best I could but I could have done much more.” (Rose Marie)

**Professional recognition**

Many participants cited professional recognition as another key challenge that they experienced. Most talked about the initial lack of understanding and recognition for the profession, with one participant claiming the profession was considered ‘the poor relation’ of the health disciplines. Participants also recalled the constant need to explain their role, justify what they were doing, fight their case, develop a vision and have it valued. Two therapists stated that they felt that professional recognition was still the biggest challenge they faced in their careers today; however, most agreed that the situation has improved significantly, though slowly, and there is now a greater understanding and respect for occupational therapy within the health services and society in general:

“I suppose I would think that occupational therapy is still considered a new profession, you still have to fight all the time to get OTs jobs, working. We’re up against it all the time, against larger professions.” (Kathleen)

“I think the earlier years were much more challenging and I think the satisfaction level became greater in my latter years’ work as an OT when I could see the recognition was coming within society in general.” (Noirin)

**Professional and personal development**

All participants reported overall satisfaction with their careers. Although they identified different areas for development within the profession, such as the need to employ more therapists or obtain more control over budgets, and despite their acknowledgment of the challenges and frustration they experienced when initiating and developing services in the 1970s many highlighted ways in which their professional experiences had provided them with a sense of appreciation for health and well-being, and a sense of perspective, contentment and balance in their personal lives. Some said their experiences had affected their own personal development, including increased confidence and the development of friendships, while others listed professional achievements, including career progression, leadership opportunities, training, and work-life balance as benefits of their careers. Most talked about the importance they attached to meeting and helping people, the satisfaction they gained from these interactions and the importance of keeping the client at the heart of their professional experiences. The following quotes from participants illustrate these experiences:

“I think it’s a wonderful profession. I think the opportunity to help people make changes in their lives is huge.” (Myra)

“I enjoyed having a career. I don’t think I’d enjoy being at home and the fact that I trained as an occupational therapist, that I got to use it all over the years.” (Kathleen)

**DISCUSSION**

This study is one of the few to explore the professional experiences of early occupational therapists in Ireland and it illustrates some of the key challenges and rewards that
accompanied these careers. For many participants, the most challenging experience was initiating and developing services with little guidance or wider understanding of their role. Considering the first programme for occupational therapy in Ireland only started in 1963 it meant that there were very few therapists working in Ireland who could support the new graduates and there were similarly few health professionals who were aware of the role they provided. This resulted in stress, frustration, isolation, uncertainty and for one participant, a feeling that time had been wasted trying to manage and develop a career and services without adequate resources and support. Although there are few other studies that explore these challenges in this detail, similar papers from around the world have also acknowledged the ‘shaky first steps’ of the 1960s and 1970s and the challenges therapists faced in asserting their value and role (Baptiste, 2011; Schwartz, 2003).

Nevertheless, many participants also cited this period as one of their most fulfilling, discussing their satisfaction at overcoming these obstacles, starting services and seeing them develop and flourish. Indeed the increase in services and the number of therapists employed was identified as the biggest development in the profession in Ireland and the participants and their peers played a key role in sowing the seeds for this achievement.

Furthermore, current practice offers a range of supports such as professional supervision, peer support, evidence-based practice, and continuing professional development and training for students, new graduates and experienced therapists alike (Health and Care Professions Council, 2012; Lee & Mackenzie, 2003). It is difficult now to imagine the reality of starting services without such support but it is important that we are aware of these beginnings to appreciate the developments undertaken and the contributions made. It is imperative that Occupational Therapy in the Republic of Ireland develops and maintains effective strategies for supporting students and practitioners in their roles, reducing professional isolation, developing job satisfaction and ensuring appropriate support for all new graduates (Lee & Mackenzie, 2003).

Professional recognition was also identified as a key struggle for participants. This reflects international literature which illustrates how members of the profession have historically felt misunderstood and underappreciated by both colleagues and the public (Turner, 2011). This situation poses challenges for the profession but it also means that clients’ occupational needs risk going unmet (Wilding, 2011). In response to these concerns Florence Clark (2012) called on therapists to embrace ‘evidence with attitude’ to create a cohesive picture of high-powered scientifically credible Occupational Therapy while also recognizing the transformational power in their own selves and in the work they perform every single day. Similarly there has been an increase in calls for therapists to take responsibility for promoting and marketing Occupational Therapy (Baum, 2006; Jacobs, 2012) while Wilding (2011) has encouraged therapists to question the dominance of medical discourses upon their practice which may have contributed to a hegemony that practice must be medicalised rather than occupation focused. In addition, Turner (2011) has described occupational therapy as a profession in ‘adolescence’, searching for its identity and vision for the future, but on the cusp of maturing into ‘young adulthood’. This transition period is reflected by the fact that the majority of participants in this study felt that recognition for the profession had developed and Occupational Therapy is well positioned in Ireland today, with increased confidence and great future potential. Notably, the two participants who said that professional recognition still remains their biggest ongoing challenge today both worked in mental health services. Although both participants reported overall satisfaction with their careers, it is noteworthy that international literature has indicated diminishing morale and higher levels of emotional exhaustion among occupational therapists working in mental health settings than those working in non-mental health settings (Bailey, 1990; Lloyd & King, 2004; Sturgess & Poulsen, 1983).

Some participants offered explanations for the gradual increase in professional recognition in Ireland ranging from increased educational efforts, continuous professional successes, on-going promotion of the value of the profession and the development of a more scientific background and language. Many participants also discussed their anticipation of upcoming statutory registration and their hopes that this would further advance professional recognition in the Republic of Ireland. Many of the participants went on to fulfil leadership and management positions in their careers thereby answering calls for directly and indirectly promoting professional recognition in different areas, whether through piloting services, introducing new ways of thinking, engaging in political activism, contributing to the organisation of the Association of Occupational Therapists of Ireland, offering practical expertise on national forums, demonstrating competent leadership skills and encouraging and promoting confidence among their colleagues and the profession. The findings highlight the importance of promoting the value of Occupational Therapy.

Additionally, it is significant that despite the challenges of developing services, achieving professional recognition, experiencing economic downturns, and being consistently short staffed all of the participants reported that overall they were satisfied with their careers. This is consistent with international literature which shows high levels of job satisfaction in Occupational Therapy (Eklund & Hallberg, 2000; Moore, Cruickshank & Haas, 2006). It is also encouraging for the future of the profession as job satisfaction has been shown to affect staff retention and work productivity (Moore et al., 2006). In addition, many participants discussed the importance of the humanistic nature of the profession, and the focus on the relationship between the therapist and client. Interviewees valued the opportunity to work with and help people and to make a difference in their lives. This characteristic has also been rated highly in similar studies (Moore et al., 2006). Furthermore, participants were grateful for opportunities for professional and personal development throughout their careers. Benefits included increased confidence,
levels of job satisfaction, along with significant
differences. Participants also noted that although all participants reported overall high
levels of job satisfaction; varied professional experiences, training and advancement; opportunities for
personal and professional development; and also individual concerns about issues such as staffing levels, recruitment, career progression and control over budgets.

The study also captures positive experiences including overall high levels of job satisfaction; varied professional experiences, training and advancement; opportunities for
personal and professional development; and also experiences which provided participants with an
appreciation for health and well-being. Together these
findings paint a picture of the varying professional experiences of the seven
occupational therapists who started working in the
Republic of Ireland in the 1970s. It provides insights into
the challenges and rewards, the satisfaction and the
frustration, that was associated with participants’ careers. Difficulties included the experience of establishing
services at a time when there was little understanding of
Occupational Therapy among the public and other health professionals; setting up new services, often single-handedly; fresh out of college with little or no support; the
challenge of gaining professional recognition; and also
individual concerns about issues such as staffing levels, recruitment, career progression and control over budgets.

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THE LIFESTYLES OF ‘GENERATION Y’ UNDERGRADUATE OCCUPATIONAL THERAPY STUDENTS: EDUCATIONAL CONSIDERATIONS

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ABSTRACT

Background: ‘Generation Y’ students are those born between 1982 and 2000. Generational theorists have proposed that this group have unique ‘characteristics’ due to the societal influences during their formative years, in particular their preference for technology, which they have assimilated into their daily lives. Consequentially, their preferred teaching and learning preferences are said to differ from older generations. The relationship between their lifestyle and educational methods does not appear to have been previously explored.

Objective: To compare the lifestyle of one cohort of Occupational Therapy students at an Australian University with the ‘Generational Y’ profile.

Methods: A hard copy survey was developed based on ‘Generation Y’ themes identified in the literature and delivered to occupational therapy student lectures.

Results: Ninety two, (40%) of students responded. All students owned a computer, with 78% accessing Facebook daily. Most students lived at home with parents and were not in regular contact with older people or young children. Most worked to fund their leisure activities, which included reading regularly but did not include playing computer games or volunteering.

Conclusion: Some aspects of students’ lifestyles indicated similarities to the ‘Generation Y’ profile, with the exception of some leisure activities. Service learning and use of technology are discussed as teaching and learning strategies.

KEYWORDS

Millennials, students, ‘Generation Y’, Facebook, Social media

INTRODUCTION

Occupational therapists consider the relationship between life occupations and other phenomena such as health, quality of life, identity, social structures and policies (Hocking, 2000). Life occupations are everyday activities and roles that we actively engage in, that are meaningful to us and have purpose. These broadly include self-care, work and leisure. As educators we know very little of the life occupations of students outside of the university. Prensky (2001) argued that “today’s students are no longer the people our educational systems were designed to teach” (p.1). The premise being that students, especially those classified as ‘Generation Y’, have developed different expectations and learning styles from previous generations due to their life experience and
lifestyle. Lifestyle is how students choose to spend their everyday lives.

Mannheim (1952) proposed the core tenets of generational theory introducing the concepts of ‘generational groups’. Over time, these groups have been named as the ‘GI generation’ born 1901-1924; the ‘Silent Generation’ 1925-1942; the ‘Baby Boomers’ 1943-1960; ‘Generation X’ 1961-1982; ‘Generation Y’ 1983 – 2002 and ‘Generation Z’ from 2003 onwards. Each group share a set of experiences during their formative years, including a particular set of social and economic conditions. These influence the generation collectively, in particular shaping their thinking, values, and beliefs, forming their ‘generational characteristics’ (Prendergast, 2009).

In Australian undergraduate education, the term ‘Generation Y’ is commonly used as a stereotypical descriptor for the majority of current undergraduate students. Shaw and Fairhurst (2008) described this group as being confident, entrepreneurial as well as collaborative and team oriented. While homogeneity is never present in any generation, one study confirmed that some generational characteristics have been observed by practice educators in Australian Occupational Therapy students (Hills, Ryan, Smith, & Warren-Forward, 2011). Earlier Occupational Therapy authors have also described generational differences in Canada and the UK but there is limited research into the characteristics attributed to this generation (Boudreau, 2009; Gray, 2008).

The most reported characteristic of ‘Generation Y’, is the integration of technology into their daily lives from their formative years (Prensky, 2001). Technology has clearly impacted on all generations; however, for this younger generation the use of technology does not present a departure from a previous way of life (Nimon, 2007). It has also been suggested that technology is inseparable from their daily existence, being of equal importance to their food and clothes, as it is essential to always be ‘connected’ to each other and to the global world (Nimon, 2007). Others have concluded that this omnipresence has blurred the distinctions between learning, work and play (McLoughlin & Lee, 2008).

Australian research has found that not all undergraduate students have access to technology, including access to a computer (Kennedy, Krause, Judd, Churchward, & Gray, 2007). This, and similar studies in Australia (Kennedy, Judd, Dalgarno, & Waycott, 2010) and England (Jones & Fox, 2009) concluded that there is a lack of homogeneity amongst students with variance in access to, use, skills and preference of technology. Additionally, the familiar interpretation that this younger generation are skilled multi-taskers, as they use various technologies whilst completing other activities simultaneously, has been critiqued as an overgeneralisation (Bennett, Maton, & Kervin, 2008). In Occupational Therapy, Hills et al (2012) reported that practice educators considered that students were “techno-savvy” but there is no research on students’ technology use to uphold this view.

As this research sought to elucidate the lifestyles of one cohort of Occupational Therapy students compared to published ‘Generation Y’ characteristics, the first aspect considered was student ownership of technology and available internet access. This was followed by students’ use of their technology including their preferences for social network and gaming sites. These aspects were particularly relevant to inform the appropriate integration of technology into curriculum design, as some previous Occupational Therapy research has indicated that Faculty chosen technology such as blogs had not been enthusiastically adopted by students. These authors recommended that a more student-centred approach, based on use and familiarity of technology, be considered if introducing new technologies into the curricula (Derdall, Mulholland, & Brown, 2010; Wiid, McCormack, Warren, Buckley, & Cahill, 2013).

‘Generation Y’ authors have suggested that technology has detrimentally impacted on recreational reading due to the immediacy of information via the internet (Rennie & Patterson, 2008; Twenge, 2009). Consequently, these authors have suggested that students have developed a ‘snatch and grab approach’ to information gathering and prefer video, audio and interactive media to texts in education (Sutherland-Smith, 2002; Twenge, 2009). Furthermore, one student study in the USA reported that ‘older generations’ spend far more time reading news, literature and fiction than those considered to be part of ‘Generation Y’ (Sweeney, 2006). Twenge (2009) reported that textbook publishers were responding to these changes by shortening undergraduate text books and editing material into easy to digest ‘chunks’. No other evidence could be found to support these statements for Occupational Therapy education, so the researchers in this study were interested to ascertain students’ engagement in reading, both text books and other reading materials such as biographies, as these are used as narratives in the curriculum, for example when exploring the lived experiences of those in palliative care services.

Curricula designers also aim for students to acquire ‘graduate attributes’ which incorporate skills and values suitable for employment such as professionalism, scholarship and global citizenship (Barrie, 2004). To achieve these outcomes both curricula and non-curricula community based activities have been found to contribute both to students’ psychosocial development and to greater academic success (Junco, Heiberger, & Loken, 2011). In Occupational Therapy, students have been placed in community settings to study an agency and to work with clients. This type of community engagement termed ‘service-learning’ has been found to promote students’ knowledge, confidence, self-perception, research skills and clinical competence, in addition to developing feelings of being ‘comfortable’ to work with specific groups of people (Atler & Gavin, 2010; Schindler, 2011).

The benefits of service-learning correspond to Higgs (2009) analysis of the impact of life experience on professional knowledge. Higgs (2009) proposed that professional knowledge is divided into propositional knowledge (research and theoretical knowledge), and non-propositional knowledge (professional craft knowledge). The latter is learned in practice placement for
most students but also includes their personal knowledge developed from their life experience and lifestyle. One aspect of student lifestyle is student employment. It is known that Australian students' lifestyles include working in paid employment, with 78% of students being in paid work for an average of 15 hours per week (Coates, 2011). ‘Generation Y’ commentators add that as a supposedly altruistic generation this group also complete community volunteering activities particularly with environmental or socio-economic projects (Howe & Strauss, 2000). To ascertain students’ lifestyle and community engagement which may impact on their non-propositional knowledge, this research included questions on the amount and type of paid and non-paid work, as well as reasons for working. As a further insight into their non-propositional knowledge, the ages of people that students come in regular contact with was also investigated. It was anticipated that this would inform the types of service-learning that would most benefit their professional development.

Social commentator Mackay (2007) reported communities in Australia are changing, particularly in living arrangements. Hillman and Marks (2002) found in a longitudinal study of Australian students that they were residing longer at home with parents, than earlier generations. This is said to be delaying adulthood, marriage and parenthood into their thirties (Power, 2012). Mackay (2007) also reported that the consequence of this was greater dependence on their parents for daily tasks particularly home management skills and called them “kid-adults”. The final part of this survey therefore investigated Occupational Therapy students’ living arrangements to ascertain if this cohort matched this generational trend. This may be important information when designing educational courses, especially on topics such as activities of daily living which includes home management.

Aims of the study
1) To gain a “snapshot” of the lifestyles of a group of Australian undergraduate Occupational Therapy students studying in a particular semester
2) To compare a group of Australian undergraduate Occupational Therapy students to the ‘Generation Y’ characteristics identified in the literature with view to exploring curriculum developments.

METHODS

Design
A survey was chosen as this method is known to be reasonably accurate, un-intrusive, and cost effective (Smith, Adachi, Mihashi, Kawano, & Ishitake, 2006; Smith, Wei, Zhao, & Wang, 2005). According to Fink (2009, p. 1) surveys can “describe, compare or explain individual and societal knowledge, feelings, values, preferences, and behaviour”. A three part survey was developed based on the ‘Generation Y’ literature, namely:

Section 1: Demographics
Four fixed choice questions on student demographics including: gender; age; and year of study.

Section 2: Lifestyle
Eighteen questions based on students’ lifestyles such as living arrangements, type of employment and hours worked; reasons for working; volunteering activities; reading habits, age groups students have regular contact with; and if students care for someone.

Section 3: Technology
Five fixed choice questions on computer use which included computer accessibility; internet access and sites accessed; approximate time spent on internet sites and computer game use.

The survey was piloted on three students and no amendments were made.

Ethics
Ethical approval for this study was granted by the Human Research Ethics Committee of The University of Newcastle, Australia.

Participants
Participants included all 228 Occupational Therapy students in the undergraduate program in an Australian Metropolitan University. This was purposeful sampling as participants were invited from a known cohort. The anonymous hard copy survey, with the participant information statement and blank envelope attached, was delivered to each year via a third party during lecture periods. Consent was assumed when the questionnaire was returned completed. Consent, withdrawal of consent, storage of data, reporting of data, anonymity and the rights of participants were covered in the Participant Information Statement.

Data Analysis
The fixed choice answers were analysed using SPSS (version 19). Cronbach’s alpha was .619 which indicated an acceptable level of internal consistency.

RESULTS

Section 1: Demographic information
Of the 228 students enrolled in the program, 92 (40%) of the questionnaires were returned completed. Of these, 82 (89%) respondents were female. Eighty five (92%) were under 30 years of age and therefore categorised as ‘Generation Y’. Respondents by year were: 1st year (13%); 2nd year (65%); 3rd year (12%); and 4th year (10%).

Section 2: Lifestyle
The survey showed that most of the ‘Generation Y’ students were in paid employment as shown in Figure 1. The food industry was the most popular employer (27%) followed by retail/sales (24%). A smaller number worked with people who were ill, disabled or occupationally deprived (17%) and in child care (7%). The smallest employment types were family business (5%) and the social and leisure industry (4%). The remainder came under “other”.


The next section asked about students' participation in reading, for both leisure and for academic purposes. Table 2 indicates the responses to types and amounts of reading by age and generation units.

**Table 2**  
**Reading by generation**

<table>
<thead>
<tr>
<th>Site</th>
<th>Never</th>
<th>Daily</th>
<th>Weekly</th>
<th>Monthly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magazines</td>
<td>Gen. Y 16%</td>
<td>Older 14%</td>
<td>Gen. Y 9%</td>
<td>Older 0%</td>
</tr>
<tr>
<td>Newspapers</td>
<td>Gen. Y 1%</td>
<td>Older 14%</td>
<td>Gen. Y 47%</td>
<td>Older 45%</td>
</tr>
<tr>
<td>Novels</td>
<td>Gen. Y 18%</td>
<td>Older 43%</td>
<td>Gen. Y 47%</td>
<td>Older 34%</td>
</tr>
<tr>
<td>Written</td>
<td>Gen. Y 16%</td>
<td>Older 0%</td>
<td>Gen. Y 8%</td>
<td>Older 14%</td>
</tr>
<tr>
<td>University</td>
<td>Gen. Y 16%</td>
<td>Older 0%</td>
<td>Gen. Y 8%</td>
<td>Older 14%</td>
</tr>
<tr>
<td>information</td>
<td>Gen. Y 2%</td>
<td>Older 0%</td>
<td>Gen. Y 12%</td>
<td>Older 14%</td>
</tr>
<tr>
<td>Text Books</td>
<td>Gen. Y 11%</td>
<td>Older 0%</td>
<td>Gen. Y 12%</td>
<td>Older 14%</td>
</tr>
<tr>
<td>Self-located</td>
<td>Gen. Y 11%</td>
<td>Older 0%</td>
<td>Gen. Y 12%</td>
<td>Older 14%</td>
</tr>
<tr>
<td>literature</td>
<td>Gen. Y 11%</td>
<td>Older 0%</td>
<td>Gen. Y 12%</td>
<td>Older 14%</td>
</tr>
</tbody>
</table>

Figure 2 shows students’ responses on age groups that they had regular contact with. Only a minority of ‘Generation Y’ students (18%) reported that they cared for someone compared to the majority of ‘older generations’ (86%). However half of this latter group reported they cared for children.

**Figure 2**  
**Age groups students have regular contact with**

**Section 3: Technology**

All the students in this survey reported they owned computers. Many ‘Generation Y’ students (44%) reported owning both a lap-top and a desk-top computer; many owned only a lap-top (44%) and the remaining owned only a desk top computer (13%). The majority (91%) reported regular access to the internet from their home, a few reported frequent access (5%) and very few (2%) reported no internet access at home. Table 3 shows student responses on the internet sites they accessed together with the frequencies of use. With regards to playing computer games, the majority of ‘Generation Y’ (74%) and all of ‘older generations’ students (100%) reported that they never played games, while some of ‘Generation Y’ (17%) reported they played computer games occasionally.
DISCUSSION

The overall response rate of 40% was calculated on the numbers enrolled in the entire cohort but as not all students were present in lectures, the actual response rate may be higher. Furthermore, the response rates between the year cohorts were unequal which is attributed to lecture attendance. However, as most of the student population was ‘Generation Y’, the expected majority of responses were from ‘Generation Y’ students, which was the focus of this study.

All student respondents reported owning a computer, with just under half owning a lap top and a desk top computer. This did not concure with the Australian research by Kennedy and colleagues who found that not all students are computer owners (2007). Nevertheless, computer prices have reduced since this study possibly making them more accessible for purchase. The majority of students also have access to the internet from home, with most of the ‘Generation Y’ group using Facebook on a daily basis.

There is growing evidence of the use of Facebook in undergraduate education. Schwartz (2009) described how Facebook was an effective method for student communication. Skiba (2010) reported on a simulation manikin called ‘Stella’ who had a blog on Facebook which is used by nursing students for discussion and review of academic work. In Occupational Therapy, Faculty established blogs were created for students to communicate with each other while on placement, but students indicated a preference for Facebook (Derdall et al., 2007).

While this research found that Facebook is part of most ‘Generation Y’ students’ lifestyle, there is some concern about professional behaviour, termed e-professionalism when leisure and work is blended, as Facebook is a public domain (Kashani, Burwash, & Hamilton, 2010; Osman, Wardle, & Caesar, 2012). This has been evident with recent examples of disciplinary action being taken by regulators against health care professionals due to inappropriate Facebook entries (Keast, 2012). However, the relevance of Facebook in student centred education cannot be ignored, as students in this study used Facebook more often than email. To encourage the use of Facebook in Occupational Therapy education Kashani, Burwash and Hamilton (2010) provided Facebook ‘Professional Conduct’ guidance and the authors advocated that using Facebook properly can promote the profession, as well as social networking between professionals establishing ‘communities of practice’. The authors also noted however some reluctance from some occupational therapists to use social networking. Nonetheless, curricula designers creating contemporary programs could consider Facebook for student communication or for developing student ‘communities of practice’. Park (2010) studied students and faculty use of social networking and reported that unlike students, faculty, who are likely to be ‘older generation’, were not all active users of Facebook. Therefore before introducing Facebook as an educational medium, consideration may need to be given to those students and possibly some faculty who may not be familiar with Facebook and require assistance in using this technology (Kashani et al., 2010).

Facebook is a Web 2.0 technology; however, other Web 2.0 technologies such as Wikis were used less frequently by students, a finding which concurs with other Australian research (Kennedy et al., 2007). For leisure, this student group reported that they used music and film sites intermittently but did not play computer games. This finding does not correlate with some American ‘Generation Y’ commentators, who have labelled this generation the ‘Nintendo generation’ due to their excessive use of gaming (Raines, 2002). On the other hand, participants in this study were using their computers on a regular basis, thereby suggesting a certain level of ‘technosavviness’. Nevertheless, there is increasing evidence of gaming being used as an educational medium in health professional education (Frazer, 2007; Graham & Richardson, 2008; Lane, 2011). One systematic review of gaming in health sciences found that the use of games generally enhances student enjoyment and may improve long-term retention of information (Blakely, Skirton, Cooper, Allum, & Nelmes, 2009). For this cohort, more research would be required on student views of gaming and this may include both age and gender, before gaming as an educational tool could be considered in this program.

The detrimental impact of technology on reading asserted by Sutherland-Smith (2002) and Sweeney (2006) was not upheld in this study as most ‘Generation Y’ students reported reading novels more regularly than ‘older generation’ respondents. Nonetheless, the limited reading of university materials and self-searched literature may be of concern to educators; but more research is required if the ‘snatch and grab’ assertion is to be upheld. However, McLoughlin and Lee (2008) argued that reading can be an isolating experience and criticise traditional text book education, advocating it does not reflect real work
that in Occupational Therapy the transfer of knowledge with the general public. Alter and Gavin (2010) argued pre-school children, even though many were working experience, reporting limited contact with seniors and proactively managed by students in partnership with approach may ensure that gaps in skills or knowledge are progress towards evidencing graduating competence, this Theory. As contemporary health professional programs in the evolution of Knowles (1984) Adult Learning personalised and self-regulated learning is required of each student. McLoughlin and Lee (2010) contend that developed from their life experience into an academic way to engage ‘Generation Y’ students and develop the essential critical reasoning skills required of 21st century practitioners.

In addition to their academic life the majority of students in this study were in paid employment, with some working over 15 hours a week, mostly in retail or social and leisure industries. Whilst historically university students have always worked, this younger group reported their main reason for working was to fund their social and leisure activities and to run a car, rather than the reason ance totally used by many students of working to pay their university fees. ‘Generation Y’ commentators have acknowledged that this group prioritises leisure, but there is some evidence of rising mental health issues as they strive to ‘do it all’ (Twenge, 2006). Few (15.3%) students in this group engaged in non-paid voluntary activities which does not match the ‘Generation Y’ stereotype of being an altruistic generation and is lower than a study by two other Australian universities that found that 27% of students regularly participated in volunteering (Mason, Webber, Singleton, & Hughes, 2006). Whilst over half of the student participants were living at home with parents, the assumption from generational commentators of reduced home making skills and delayed adulthood may be a reality but is not proven in this study.

However, this insight into student lifestyles raises deeper educational concerns particularly how to integrate and build upon each student’s individual knowledge developed from their life experience into an academic program aimed at achieving graduating competence for each student. McLoughlin and Lee (2010) contend that personalised and self-regulated learning is required of 21st century education, proposing new pedagogies such ‘heutagogy’ or self-determined learning, as the next stage in the evolution of Knowles (1984) Adult Learning Theory. As contemporary health professional programs progress towards evidencing graduating competence, this approach may ensure that gaps in skills or knowledge are proactively managed by students in partnership with educators.

The students in this study identified gaps in their life experience, reporting limited contact with seniors and pre-school children, even though many were working with the general public. Alter and Gavin (2010) argued that in Occupational Therapy the transfer of knowledge from classroom to practice is difficult but they found that students with little or no life experience with a particular client group developed knowledge and confidence after engaging in service-learning. Service learning may be one method of building on students’ non propositional knowledge, developing relevant life experience whilst initiating student ownership of evidencing competence.

Study Limitations
Non response bias is a potential limitation. On the other hand, this study did target all Occupational Therapy students in the program and we are confident that the findings are relevant. Nevertheless, due to local sample, the results may not be generalised within Australia or Internationally.

Further research is indicated on students’ level of ‘technosavviness’, the impact of the student lifestyle on their mental well-being, and the use of Facebook as an educational medium in pre-registration education. More detailed research on the type of technologies used, e.g. smart phones and hand held tablets, is also indicated as the immediacy of information may be relevant to educational initiatives.

CONCLUSION
Overall, this research provides an insight into students’ lifestyles which, for the most part, do appear to fit into the ‘Generation Y’ stereotype with the exceptions of involvement in volunteering, reading and gaming. Most students were in paid employment to pay for leisure and their car expenses. Students reported not having regular contact with the very young and older people and this could be a focus of service learning. Most ‘Generation Y’ students use Facebook on a regular basis and this medium may be an appropriate technology to implement into the curricula. Used ethically, social networking may have the potential to promote originality and creativity by using the collective intelligence of student ‘communities of practice’ and therefore may ultimately benefit the profession in ways we cannot yet predict.

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DEVELOPMENT OF A COMPETENCY-BASED ASSESSMENT FORM FOR OCCUPATIONAL THERAPY PRACTICE EDUCATION IN TWO IRISH UNIVERSITIES.

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ABSTRACT

This report focuses on the development of an Occupational Therapy competency-based practice education assessment form across two Irish university undergraduate programmes from 2009 to 2012. It describes the consultation process resulting in a competency based assessment form that:

(a) Allows clinical educators to assess students on demonstrable performance using four categories; competence is “enhanced”, “evident”, “emerging” or “not evident”.

(b) Translates across the range of practice education settings.

(c) Is developmental; the number of expected competencies rises as the student progresses through the programme.

(d) Is based on the entry-level competencies expected of graduates developed by the Therapy Project Office in 2008 (TPO 2008b).

Feedback on the initial roll-out of the forms was sought in online survey format from students, clinical educators, and practice tutors. One hundred and fourteen surveys were completed. The responses were broadly positive and the forms were adopted for use. The survey highlighted areas that could be addressed in future training workshops for practice educators.

KEYWORDS

Practice Education, Competency-based Assessment, Undergraduate Education

INTRODUCTION

Practice education is a critical component of Occupational Therapy education and is central in undergraduate programmes worldwide (Copley & Nelson, 2012; Rodger et al., 2011). It provides students with the opportunity to develop the knowledge, skills and attitudes essential to Occupational Therapy practice. A sensitive and effective method of evaluating practice education is essential to ensure that graduating students meet the competency required to practice. In the context of professional education, competence can be understood to mean “an individual’s capability and demonstrated ability to understand and do certain tasks in an appropriate and effective manner consistent with the expectations for a person qualified by education and training in a particular profession or speciality thereof” (Kaslow, 2004, p.775). It is an assessment approach designed to demonstrate the outcomes of the education process (Jippees et al., 2012). Competency-based assessment of health professionals arose primarily from a desire for effective, safe, quality, health-care, and was driven by the public, accreditation bodies and government, and is now a feature of education for most medical and health professionals (Belar, 2009; Lurie, 2012).

While assessment of practice education has been a long-
standing part of Occupational Therapy education with competency based assessment being utilised by all four universities, the publication of entry level competencies for Health Professions in 2008 by the Therapy Project Office (TPO, 2008b) and a commitment by Trinity College Dublin (TCD) and the National University of Ireland Galway (NUI Galway) to review the forms in use led to the development of a new competency based evaluation for all four years of the Occupational Therapy courses in both TCD and NUI Galway. This article details the consultation process adopted and the collaborative mechanisms which led to the development of a new competency based practice education assessment. It outlines the rationale for the decisions regarding which competencies were included, the method of grading and the final format of the assessment. This will be presented in three parts; the consultation process, the development of the assessment forms and finally the implementation of the assessment forms including feedback gathered from students, practice educators and the practice education teams at each university. Due to the changing language related to practice education internationally and nationally the key terms related to practice education have been outlined in Table 1

Table 1. Definition of Practice Education Terms

<table>
<thead>
<tr>
<th>Practice Education</th>
<th>The placements that students complete in order to develop professional reasoning and technical skills (Mattingly &amp; Fleming, 1994).</th>
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</thead>
<tbody>
<tr>
<td>Practice Educator</td>
<td>“The individual therapists who educate, monitor and mentor students when they are on placement” (Therapy Project Office, 2008a, p.16).</td>
</tr>
<tr>
<td>Practice Education Co-ordinator (PEC)</td>
<td>Post based in the Higher Education Institution (HEI). Their role is to “co-ordinate, strategically manage and develop the quality and capacity of practice education for students” (Therapy Project Office, 2008a, p.15).</td>
</tr>
<tr>
<td>Practice Tutor (PT)</td>
<td>“The purpose of the post is to develop the capacity and quality of the practice education programme and to support both students and Practice Educators” (Therapy Project Office, 2008a, p.15).</td>
</tr>
<tr>
<td>Regional Placement Facilitator (RPF)</td>
<td>“The purpose of the post is to develop the capacity and quality of the practice education placements and to support both students and Practice Educators in the development of student training healthcare facilities in a defined geographical area” (Therapy Project Office, 2008a, p.15).</td>
</tr>
</tbody>
</table>

THE CONSULTATION PROCESS

In 2009 TCD and NUI Galway committed to review the practice education assessment forms being used and the method of grading the students on practice education placement. These forms had been in use for over ten years and apart from early examinations for perceived reliability and validity published by O’Neill in 2001 no further follow up or exploration had been completed. During the proceeding time, the new Occupational Therapy undergraduate programme in NUI Galway was established, and had begun to use these assessment forms also. A project team was established with input from the practice education co-ordinators, lecturers and the heads of the occupational therapy programmes at both TCD and NUI Galway.

The original assessment form was utilising a competent/not competent grading system with students marked as either competent or not competent on a range of competencies. Some of the competencies were desirable and some were essential; students being required to achieve all essential competencies in order to achieve an overall competent grade for each placement level. The same competencies were graded for students at all levels of the undergraduate course. In other words, second year students were marked using the same list of competencies as fourth year students. While there was an area on the assessment forms for half-way comments, there was no facility to actually grade the student’s performance at the half-way stage of a placement. In order to get feedback from stakeholders in Occupational Therapy practice education to inform changes to the existing assessment forms, an online questionnaire was developed. The questionnaire sought feedback on the components outlined above and also included open-ended questions asking for feedback on what was effective and what needed improvement in the form. The survey link was emailed to all sites on both the TCD and the NUIG placement databases and the Occupational Therapy managers list (n=58). Student feedback from TCD students was sought both through the online survey and during a return day for the fourth year students (n=160 students). The AOTI practice education committee (n=6) and the TCD Practice Education Team (n=7) were also invited to respond. The questionnaire elicited responses from forty-eight Occupational Therapy practice educators, thirteen Occupational Therapy managers, five practice education team members (one practice education co-ordinator, one regional placement facilitator and four practice tutors), one lecturer and fifty-nine students. Feedback collated indicated that respondents believed that:

- The use of competent/not competent is an effective method of assessing practice education but the grading system should be updated to include a scale of competence, rather than just the option of competent or not competent.
- All competencies included on each assessment form should be essential, with the removal of desirable competencies.
- The assessment form should contain a section for formative scoring at half-way to act as a guide to the student’s performance and competency achievement at the half-way point of the placement.
- The assessment form should be available electronically.

This initial stage in the development of the new assessment forms also involved consultation with the Association of Occupational Therapists of Ireland (AOTI) and Occupational Therapy representation from the Therapy Project Office (TPO) and communication with the occupational therapy programmes at the University of Limerick (UL) and University College Cork (UCC).

THE DEVELOPMENT OF THE ASSESSMENT FORMS

There was consensus from the outset of the project to remain committed to the principle of competency-based practice education assessment. A previous review of the
assessment of Practice Education had found that this form of assessment was highly valued by TCD and NUI Galway. The key questions regarding the development of new assessment forms were:

i. What grading system would provide an effective evaluation mechanism to measure performance and encourage student learning and development towards competent performance?

ii. Which competencies should be included in the assessment and which should be demonstrable by the students at particular stages of their development?

**Grading System**

Results from the questionnaire circulated in 2009 indicated that the grading system on the form was of particular concern to stakeholders, and needed to be updated. In addition to seeking feedback by questionnaire, the project team met with practice education co-ordinators in other disciplines at TCD (physiotherapy and speech and language therapy). Information was sought on the grading systems that they used in their practice education forms and this information was then supplemented by a review of other assessment forms used across health science disciplines both nationally and internationally. In Australia, Occupational Therapy students are assessed on a five-point scale of competence, and a recent review confirmed their continuing use of this method (Turpin, Fitzgerald & Rodger, 2011). Other universities use a numeric rating scale such as the Competency-Based Fieldwork Evaluation (CBFE) (Miller et al., 2001). This review process informed the decision making on the grading system to use in the new assessment forms, with the following being agreed for implementation:

- The use of a four-point scale of competence using the grades “not evident”, “emerging”, “evident” and “enhanced”; the former two grades are “not competent” grades and the later two grades are “competent” grades. The grades are defined in Table 2.

<table>
<thead>
<tr>
<th>Not-Competent Grades</th>
<th>Competent Grades</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Not Evident” – This competency was not demonstrated</td>
<td>“Evident” – This competency was consistently demonstrated</td>
</tr>
<tr>
<td>“Emerging” – This competency was not consistently demonstrated</td>
<td>“Enhanced” – This competency was consistently demonstrated. The performance was to a high standard</td>
</tr>
</tbody>
</table>

- Replacement of the term “learning objective” with the term “competency”. This makes explicit the fact that the new practice education assessment forms utilise competency-based assessment principles.

- All competencies included on each assessment form will be essential. The student must achieve a competent grade (i.e. “evident” or “enhanced”) in every competency on the assessment form in order to achieve an overall grade of competent for the placement.

Each competency can be graded at the half-way stage of placement (formative assessment) and at the end of placement (summative assessment).

**Selection of Competencies**

The project team completed a substantial review of the competencies included in the previous assessment forms, the undergraduate curricula in both TCD and NUI Galway and the entry level practice competencies published by the TPO (2008b); and following extensive drafting, discussion and debate, the project team developed three specific assessment forms. The first, entitled “Level I” was developed for the first practice education experience completed within the first year of education and consensus was reached to include only eight specific competencies. Students are required to:

- Work safely in compliance with health and safety regulations as specified in the practice setting
- Adhere to the ethical, legal, professional and local practice contexts that inform Occupational Therapy practice
- Adhere to confidentiality as described in the local context
- Present self in a manner appropriate to the working environment
- Adhere to specified personal and professional boundaries within practice
- Demonstrate a positive approach to clients and team members
- Demonstrate effective time management
- Communicate effectively and in a professional manner with individuals

This placement level is short in duration and aimed at principally introducing students to the Occupational Therapy practice context and the professional behaviours expected of them within this context.

For the remaining levels of practice education assessment, competencies were divided into five categories based on the Therapy Project Office (2008b) Occupational Therapy Competency guidelines, the occupation-focused ethos of the undergraduate programmes and the desire to develop professional and self-directed learners:

1. Occupational Competencies
2. Communication Competencies
3. Occupational Therapy Process Competencies
4. Professional Behaviour Competencies
5. Professional Development Competencies

This assisted the team in establishing the practice education competencies it would be reasonable to assume that the students could achieve at each of the remaining stages of their development of knowledge, skills and attitudes. A second form entitled “Level II” was created for use with students on their second practice education experience with 36 competencies included. The final form entitled “Level III” was designed for assessment of students in their third and fourth practice education placements and has 49 competencies.
Implementation of the Assessment Forms

The final drafts of the assessment forms were submitted to TCD’s Bologna Desk to ensure that they met the stipulations of the Bologna Declaration, 1999, in relation to appropriate learning outcomes. Approval was granted and the assessment forms were then sent for graphic design and creation. These forms were approved by both TCD and NUI Galway and their use was implemented with all student cohorts during the academic year 2011-2012. As part of the development process, collection of stakeholder feedback during the roll out process was considered essential. Online feedback was sought from students, practice educators and practice education team members during the implementation period by the use of an on-line survey.

STAKEHOLDER FEEDBACK

Participants

The survey was forwarded to the student contact in each of the sites facilitating a student (160 students from TCD and 25 students from the second year in NUI Galway) requesting that the survey details be shared with practice educators involved in any part of the students’ practice education experience. One hundred and fourteen individuals responded to this survey. Thirty eight percent (n=43) were students, 57% (n=65) were practice educators, and 5% (n=6) were members of a practice education team i.e. practice tutors or regional placement facilitators. The majority of respondents (82%) were either TCD students or those who had taken a TCD student on placement during 2011-2012.

Survey Results

The results of the survey are outlined in Table 3.

<table>
<thead>
<tr>
<th>How did you find the assessment form to complete?</th>
<th>Very Difficult/Difficult</th>
<th>Undecided</th>
<th>Straightforward/Very Straightforward</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.9% (n=9)</td>
<td>10.5% (n=12)</td>
<td>81.6% (n=93)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How clear was the grading system?</th>
<th>Very Unclear/Unclear</th>
<th>Undecided</th>
<th>Clear/Very Clear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Unclear/Unclear</td>
<td>11.4% (n=11)</td>
<td>7.9% (n=9)</td>
<td>80.7% (n=92)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How clear were the competencies to understand?</th>
<th>Very Unclear/Unclear</th>
<th>Undecided</th>
<th>Clear/Very Clear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Unclear/Unclear</td>
<td>13.8% (n=18)</td>
<td>10.3% (n=12)</td>
<td>73.7% (n=94)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How appropriate was this assessment to the student’s year of study?</th>
<th>Not at all Appropriate/Not Appropriate</th>
<th>Undecided</th>
<th>Appropriate/Very Appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.9% (n=9)</td>
<td>9.6% (n=11)</td>
<td>82.4% (n=94)</td>
<td></td>
</tr>
</tbody>
</table>

Respondents were also asked if there were any competencies that should have been included but were not included. 95% of individuals answered either “No” or “Don’t Know” to this question. Similarly, when asked, only 8% of those asked could identify competencies that should have been excluded. This demonstrates that the competencies on the form are generally well-selected.

Although not specifically asked for in the survey, there were a large number of positive comments in relation to using the assessment as a teaching tool on placement. These individuals felt that marking the student at halfway “is helpful ... to highlight areas for further development and attention in second half of placement”. It was also felt that the new grading system and competencies “enables greater sensitivity”. This grading system is intended to be used as a teaching tool, so it was positive to see individuals finding that it “captured the skills and areas requiring further attention of the student”, “assisted with giving feedback” and from a student’s point of view “was a great tool to receive constructive criticism”.

AREAS FOR FUTURE DEVELOPMENT

Because of the generally positive feedback towards these forms among practice educators, students and the practice education teams, it was decided to continue with their use without further changes. However, the feedback in the above survey highlighted some areas that are outlined below and that will feature in future practice education training.

It was noted by some respondents that when the nature of the clinical practice meant that students were not afforded much opportunity to demonstrate their skills that it can be difficult to mark the student as competent. One example of this was when “discharge planning/onward referral” did not happen during the student’s placement. In certain settings it may be necessary to consider the handing-over of their client work to the occupational therapist at the end of placement when grading this. It was felt by three individuals that it would be difficult to mark students on competencies relating to meaningful occupation in Primary Care settings where the focus is on “equipment provision for safety and independence in the home”. As occupation is the primary focus of the profession, both universities felt that these competencies should remain on the form. Competency in participating in groups may be assessed by observing the student’s participation in professional groups such as the multidisciplinary team. As stated by one respondent “some (competencies) require a lot of discussion and interpretation to decide on what they actually mean in clinical practice”. The universities support and encourage this debate and discussion, and feel that each clinical area should discuss what they expect of a student on placement, in conjunction with the practice education staff.

Competencies that respondents stated should be added to the forms included “self-directed learning”, “taking an active role in the department”, “presenting a case study”, “knowledge of the roles of other MDT members” and “observation skills and client occupations”. While these statements do not specifically appear on the forms the project team would argue that they are inherent in the competencies presented, particularly in the “Professional Development” competency category. A lack of clarity regarding what constituted performance in each of the grades was noted by some of the respondents with guidance sought as to “what distinguishes an evident competency from an enhanced competency”. Both universities hold practice education training workshops, and the discussion of this issue will form part of this training in the future. Eight respondents (7%) stated that the second year form contained competencies that would not be expected at second year level. Comments included; “you do not expect a second year student to be competent...”
at all”. Two individuals (2%) stated that “prioritise and manage a caseload” is not an appropriate competency for a second year student. The project team acted to maintain these competencies contending that a second year student should be able to contribute to a caseload appropriate to their clinical area. Finally there were suggestions made regarding the formatting of the assessment forms. These ranged from statements about the order of the competencies to specifics about the layout of the student hours log, areas for signatures, and comment boxes. Educators were eager that the form should be available to be filled in on the computer. These formatting issues will be addressed with the assistance of administration staff in the two universities.

CONCLUSION

This report outlines the collaborative development of new competency-based practice education assessment forms for the Occupational Therapy programmes in two Irish universities. The new assessment forms have incorporated feedback and consultation from students, practice educators, lecturers, Heads of Discipline and practice education staff. Not only are effective competency-based practice education assessment forms essential in ensuring students meet the competency required by graduating occupational therapists, they can also function as useful tools for education and learning. By developing the competencies to be assessed in line with the TPO entry level competencies for practice the universities can clearly demonstrate that their graduates meet the standards required to enter practice. Future development will include a review of the forms and discussion with practice educators on how to integrate and use the forms within their practice setting.

REFERENCES


The second chapter is written by Dr Mary Law and presents The McMaster Lens for Occupational Therapists, which provides a conceptual framework for integrating theory throughout practice. This “telescope” model has eight lenses (Occupation, Spirituality, Development, PEO, Theoretical Approach, Assessment, Treatment and Outcome) and an adjustment ring to allow for fine tuning during each stage. While this does appear to be a useful method of conceptualising how we work with our clients during the stages of the occupational therapy process, it is somewhat disconnected from the rest of the book and is not utilised in the chapters that follow.

Each of chapters three to seven focus on a specific transition for a specific population. On the surface this could be interpreted as a limitation in that in our practice in Ireland therapists are most likely to be working with a specific group such as people with mental health difficulties, physical and sensory disabilities etc and all the chapters may not appear to be relevant to all. However, the key concepts described and presented have a far wider relevance than the diagnostic categories chosen and the transitions have application to most services for people with disabilities. Chapter three focuses on the transition from home to independent living arrangements for young adults with physical disabilities, chapter four on community participation through work experience for youth with developmental disabilities, chapter five the transition to post-secondary school education for youth with learning difficulties using assistive technology, chapter six on employment transitions for youth with mental health issues and chapter seven on socialization and leisure pursuits for youth living with obesity. All of the chapters consider the person and the transition using the PEO framework and the points made are very valuable and pertinent to practice. All of the chapters provide useful case studies that personalise the information and make it more relevant to the reader. Chapter three, presenting the transition to independent living for a teenage boy with cerebral palsy, is the most detailed, moving through the occupational therapy process, highlighting each stage and even providing therapy goals and a description of how the goals can be met. Particularly for the student or novice practitioner, this would have been a useful framework for all of the chapters to follow.

The final chapter of the book relates transition specifically to the occupational therapist and highlights that occupational therapy can be central to intervention in this area. It identifies an increased focus on self-determination, a shift in focus from independence to interdependence, development of peer mentorship and the use of community building strategies as important components for development in the area of transition and transition services. Throughout the book there are arguments for early preparation for the transition to adulthood and arguably this should be informing goals of interventions for people with disabilities from a very early age, making this book as relevant to paediatric occupational therapists as to therapists working within adult services.

This book provides a useful guide to how occupational therapists can focus on transition. It is timely in relation to occupational therapy services in Ireland and is highly recommended reading.
“Occupation: Awakening to the Everyday”, hosted by University College Cork (UCC) and Occupational Science Europe, was held at UCC from the 5th - 7th September 2013. International and national speakers from 10 countries gathered to share their latest research and newest ideas about everyday occupations. Papers ranging from new practice ideas to research findings and theoretical dialogues engaged 116 participants in stimulating, forward-thinking discussions. The conference was launched with an art exhibition in Jennings Galley. Students who had participated in a six-week apprenticeship with either the Cork Printmaker or Frances Leach of Cork Textile Network displayed their prints, textiles and reflections about their creative journeys. In response to the display Dr. Elizabeth Yerxa, an honored guest stated “Your (the students) vision, humanity and humility have inspired and sustained me on my own professional path.”

The conference featured two keynote speakers: Dr. Elizabeth Yerxa, Professor Emeritus, University of Southern California and Dr. Peter Kearney, Professor Emeritus, University College Cork. Dr. Yerxa, the founder of the discipline of occupational science spoke about “Nurturing the Human Spirit for Occupation: Promoting Individual Flourishing”. She explored the biological, psychological and spiritual roots of occupation, how the human spirit can be nurtured for occupation, and how being seized by one’s occupation can influence health and the “opportunity to find joy and meaning in one’s actions and satisfaction in the everyday”. Dr. Peter Kearney, a paediatrician and anthropologist presented “The Power of Playful Mimesis: Experiences of admired achievements in an enclosed setting can transform the health of seriously ill children.

In his talk, Dr. Kearney used concepts from Victor Turner and Rene Girard to analyze the therapeutic value of Barretstown for the children who attended. Both keynote speakers highlighted the power of occupation in transforming people’s lives and the responsibility of occupational therapists to embrace occupation in their therapy.

A primary goal of this conference was to encourage networking among the participants and presenters. Social and cultural occupations including bike riding, bus tours, afternoon tea, a mindfulness session, campus tour and pubbing with authentic Irish music were organized with the premise that “doing together” triggers new ideas and relationships with the overall goal of furthering occupational science and occupational therapy.

The conference marked the 10th anniversary of the Occupational Therapy Programme at University College Cork, celebrating its mission to “generate new understanding about the complexity and power of occupation in everyday life; and the relationship to human development, health and well-being for individuals and society.” President Michael Murphy who opened the conference praised occupational science and therapy for being one of the disciplines needed in a highly functioning health care team and why he supported the establishment of the program 10 years ago.

The program opened with Irish dancing by Louise Horgan, a first year student, and closed with a video of pictures taken throughout the conference and an Irish Blessing May the Road Rise to Meet You sung by Stacey Taylor, a fourth year student.
Using a longitudinal narrative approach, I examined the lived experience of female breast cancer in Ireland from an occupational perspective with particular interest in the potential health-promoting qualities of occupational engagement in a creative activity, namely the traditional Irish handcraft of crochet.

Informed by critical theory, using occupation as a unitary concept and working primarily with feminist existential phenomenology, I developed the concept of *breasted occupation*. I defined it as both the implied notion and actual performance of occupations associated with women as a result of anatomical structure, biological processes and functional capacities within socio-cultural and historical context. This theoretical framework emphasised the importance of being breasted to female occupational beings in Western hetero-normative culture for self-image and occupational identity. Following ethical approval, ten Irish women were recruited through purposive sampling at a cancer-support centre. All chose their own pseudonyms. Three in-depth semi-structured interviews were undertaken over three years to gather the women’s personal occupational narratives. Crochet was introduced through ten group-based classes to seven of the ten women after the first interview round to examine the process of acquiring a novel creative skill and to investigate their ongoing engagement in crochet over time. Audio interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis. Video and photographic data were used to enhance the interpretative process.

The findings demonstrate the distress associated with the profound loss of a familiar body from both physical and aesthetic perspectives. They further reveal the distinct negative consequences for occupational integrity and resultant health and well-being when one’s established doing is damaged. The illness experience was found to be further negatively influenced by internalised dominant socio-cultural values about the female breast. The women’s occupational transitions to life post-breast cancer were found to occur through a painful trial-and-error process that attempted to create a new equilibrium between occupational identity and altered function. The successful reconciliation of altered functional capacity with satisfactory occupational performance resulted in a return to a personal sense of occupational integrity that enhanced sense of health and well-being. Meaningful occupational engagement in creative activity was found to assist this process. The integration of a novel activity into the occupational repertoire was found to occur through a complex embodied process of incorporation, revealing the integral mind-body nature of the occupational being which challenges the current emphasis on the mind over the body.

I propose the concept of *occupational suffering* as an intimate subjective experience that is distinct from occupational disruption which is seen as temporary, or occupational deprivation which occurs as a result of external factors. Occupational suffering is an existential response to irreversible or only partially redeemable damage, and is complexly related to senses of loss, challenges to occupational identity and to threats to subjective narrative coherence. A model of *occupational fidelity* is articulated to describe the drive to calibrate one’s doing with one’s being in order to confirm an intuitive ideal of occupational performance, experienced as a subjective feeling of rightness in one’s doing, that affirms occupational identity and nourishes one’s becoming. Engagement in creative occupations and novel projects is proposed to assist in reconciling personal occupational performance as subjectively desired, with the functional capacities of the embodied self as lived. It is argued that this is because of the personally significant occupational meaning attached to intentional embodied action. Subjectively validated occupational fidelity contributes to a sense of stable and coherent occupational identity that is consubstantial with a personal sense of...
health and well-being. These insights contribute to an occupation-focused psycho-oncology and support the importance of an occupational perspective on the subjective appraisal of health and illness within the lived breast cancer experience.

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PhD Conferring

AN EXPLORATION OF THE PROCESS OF ASSESSING FITNESS TO DRIVE AFTER STROKE WITHIN AN IRISH CONTEXT OF PRACTICE.

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Dr. Tadhg Stapleton completed his PhD at the Discipline of Occupational Therapy Trinity College Dublin in October 2012. The title of his thesis was ‘An Exploration of the Process of Assessing Fitness to Drive after Stroke within an Irish Context of Practice’. Dr. Stapleton was funded through a Health Research Board (HRB) Research Training Fellowship for Healthcare Professionals.

SUMMARY OF THE STUDY

Despite international research and recommended gold standard practice, determining fitness to drive after stroke within the Irish context of practice is a process lacking in agreed protocols or guidelines. At the time of commencement of the PhD study this was an area of occupational therapy practice that had not been researched prospectively in the Irish context. Currently, in Ireland, both phases of assessment (off-road and on-road) are fragmented and have developed in an isolated manner, and the research study was designed within the constraints of this service delivery model. The aim of this study was...
to explore the process of assessing fitness to drive after stroke within an Irish context of practice, with particular focus on the occupational therapy contribution within this process.

A sequential mixed method approach using a follow-up explanation model was utilised. The study was designed around two main phases of data collection. Phase one of the study was primarily quantitative and consisted of an initial consensus meeting followed by a prospective clinical study. Phase two utilised semi-structured interviews to provide a qualitative follow-up explanation.

An initial consensus meeting was conducted using nominal group technique (NGT) involving 13 occupational therapists. NGT findings were amalgamated with international literature recommendations and informed the occupational therapy off-road assessment protocol used in the subsequent prospective clinical study. Forty-six stroke patients were recruited to the clinical study conducted over a 22 month period. The overall clinical impression of the assessing therapist measured on a visual analogue scale was the off-road measure that was most sensitive in detecting the group of patients (n = 11) who did not complete the on-road test (P < 0.001). Of the 35 patients who did complete the on-road component none failed the on-road test, although a small proportion (n = 8) were advised to restrict their future driving. Subsequent analysis was limited by the lack of a fail group for comparison. Restricted drivers were found to score significantly worse on some commonly available measures of attention and executive functions, particularly tests with a timed component, than the unrestricted drivers. The ADSES (Adelaide Driving Self Efficacy Scale), a measure of driving efficacy and self awareness was sensitive to detect patients who may need to restrict their future driving. Standardised assessments typically recommended in the international literature such as the Trail making Test B and the MVPT were not found to differentiate between the restricted and unrestricted drivers in this study.

The qualitative follow-up interviews with 17 senior occupational therapists, seven stroke consultants and two driving assessors provided some background understanding of the unexpected findings in the clinical study. An undocumented clinical based stratification and filtering process resulting in selective referrals for formal driving assessment was uncovered. A formative approach to clinical based assessment beyond the use of standardised assessments was influential in the decision making process with regard to driving suitability. Observable rather than measurable deficits, particularly deficits of insight and awareness, impulsivity, alongside functional manifestation of cognitive, perceptual or executive deficits were more influential in the clinical decision making process than scores on standardised tests in isolation. A period of prolonged contact with the patient was preferential to observe functional performance and possible areas of deficit that would influence the clinical decision regarding fitness to drive after stroke.

Driving literature has tended to focus on assessment of the tactical and operational levels of driving; this study highlights the importance of assessment and functional observation of more strategic level skills in the initial screening and stratification for driving suitability. This undocumented pre-screening and stratification process may explain the 100% on-road success rate observed in the clinical study, and this clinical based decision making by therapists and doctors practicing at a generalist level may perhaps be a very accurate process in selecting stroke patients who are likely to successfully pass subsequent on-road testing. As the first study of its kind in Ireland these findings form a basis for future clinical practice and research in the area of assessing fitness to drive after stroke in Ireland.

PUBLICATIONS


Therapists find it challenging to integrate research evidence into their clinical decision-making because it may involve modifying their existing practices. Although continuing education (CE) programmes for evidence-based practice (EBP) have employed various approaches to increase individual practitioners’ knowledge and skills, these have been shown to have little impact in changing customary behaviours. To date, there has been little attempt to actively engage therapists as collaborators in developing educational processes concerning EBP.

The researcher collaborated with seven clinical therapists (one occupational therapist, four physiotherapists and two speech and language therapists) enrolled in a new post-qualification Implementing Evidence in Therapy Practice (IETP) MSc module to monitor and adapt the learning programme over ten weeks. The participating therapists actively engaged in participatory action research (PAR) iterative cycles of reflecting → planning → acting → observing → reflecting with the researcher.

Mixed methods were used to evaluate the IETP module and its influence on therapists’ subsequent engagement in EBP activities. Data was gathered immediately on completion of the module and five months later. Immediate post-module findings revealed four components as being important to the therapists: 1) characteristics of the learning environment; 2) acquisition of relevant EBP skills; 3) nature of the learning process; and 4) acquiring confidence.

The two themes and sub-themes which emerged from individual interviews conducted five months post-module expanded on the four components already identified. Theme 1: Experiencing the learning (sub-themes: module organisation; learning is relational; improving the module); and theme 2: Enacting the learning through a new way of being (sub-themes: criticality and reflection; self agency; modelling EBP behaviours; positioning self in an EB work culture). The therapists’ perspectives had by then shifted from that of a learner to that of a clinician constructing a new sense of self as an evidence-based practitioner.

Findings from this study underline the importance of the process of socially constructed knowledge and of empowering learners through collaboratively designed continuing education programmes. In the student-driven learning environment, therapists chose repetitive skill-building and authentic problem-solving activities which reflected the complexity of the environments to which they were expected to transfer their learning. These findings have implications for educators designing EBP continuing education programmes, during which students develop professional ways of being.
PhD Conferring

BUILDING A SUSTAINABLE WHEELCHAIR AND SEATING PROVISION COMMUNITY - MEETING PEOPLE’S PRIMARY NEEDS NOW AND IN THE FUTURE

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ABSTRACT

Choosing a universal model perspective based on equality and human rights, wheelchair and seating assistive technology (WSAT) is seen as an enabler both extrinsically and intrinsically for people with posture and mobility impairments to actively participate across their life span in everyday living. The value placed on providing an appropriate wheelchair as a basic human right appears to be misunderstood, placing less urgency on the development of sustainable wheelchair provision, which is economically viable to meet people’s needs now and in the future. Wheelchair provision internationally faces enormous pressure to provide a more uniform and unified service. The provision of a wheelchair and seating is a complex system to understand, as there are a multitude of influences involved, from design to the follow-up and management of WSAT to meet individual requirements. The focus of this doctoral thesis was wheelchair and seating provision in the Republic of Ireland, which has developed and grown rapidly over the past twenty years, seeing an increase in localised, more accessible specialist services and the availability of advanced technology. However, even with these positive developments, current wheelchair provision lacks uniformity and could not be regarded as sustainable.

Given this, the research sought to create a collaborative model of practice that included social, environmental, economic and political responsibilities of all identified stakeholders. It acted on the basis that a change in policy was required to make effective provision. A qualitative research design utilising a soft systems methodological framework which included organisational ethnography and critical participatory action research was chosen to study this complex system. The soft systems approach is a long-standing generic participatory method, designed to act as a vehicle for negotiation among stakeholder groups, who share a common goal. A research partnership with SeatTech, Enable Ireland’s custom posture and mobility service was established as a host institution. The research process involved participant observation, individual interviews and a series of collaborative workshops, involving thirty-five key stakeholders. The process was made up of four main pillars, these included: Stakeholder Identification (Pillar 1); Understanding Perspectives (Pillar 2); Meaningful Collaboration (Pillar 3); Strategy Development (Pillar 4).

Findings revealed that the importance of wheelchair and seating provision appeared to be invisible within the Irish government discourse, with current provision nationally not in keeping with the overall guidelines set out by the WHO (2008). The evidence suggested some improvements; however developments appeared ad hoc, piecemeal and incomplete, leaving services users and service providers in a constant liminal state. Key issues identified by participants appeared to impact greatly on the pace of system causing stress, frustration and fear. The main areas of concern included waiting times, standards of provision relating to unregulated wheelchair procurement; deficits in education and training; poor follow-up and management; no emergency services and the impact of the current recession.

A proposed strategy document for sustainable change in wheelchair and seating provision was produced. A model for building sustainable wheelchair and seating communities of practice (SCOP) also emerged, which could be applied as part of a necessary review for national wheelchair and seating provision recommended as a result of this study. This model could also link in with the implementation of international guidelines to build sustainable wheelchair and seating provision, meeting peoples’ primary needs now and in the future.
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