

Occupational Therapists' Understanding of Autonomy for People with Dementia

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Abstract:

The purpose of this qualitative descriptive study was to investigate the views of occupational therapists at one of New Zealand's largest District Health Boards (DHBs) regarding their understanding of autonomy for people with dementia in relation to placement decision making.

Using purposive sampling, six participants were individually interviewed using a semi-structured interview template. Interviews were digitally recorded, transcribed verbatim, and thematically analysed.

The results of the study indicate that despite therapists having a theoretical understanding of autonomy, there are significant barriers to effective practical implementation for people with dementia. People with dementia are often cared for by an occupational therapy workforce which is inexperienced in dementia care (in a general health setting), with capacity status used reactively by the multi-disciplinary team and largely in situations where a decision is being forced upon a person with dementia. Access to the required skilled government funded caregiving support is lacking and proves a major determinant of placement along with other factors including perceived risk to the person by the placing therapist. Patient choice seemingly plays little role in the placement decision-making process.

Introduction

Autonomy is defined as “the right of the individual to be self-determining and to make independent decisions about his or her life” (Kanny & Slater, 2008, p. 194). In a medical context, respect for a patient's personal autonomy is considered one of many fundamental ethical principles, yet, in his seminal essay on the subject (1986), Dworkin questions how far a person with dementia is permitted the right to make a decision for themselves that others would not deem to be in their best interest.

Occupational therapists, with their unique focus on occupational performance, have a pivotal role in placement decision-making. The question of autonomy is frequently at stake in the medical decision-making process (Dworkin, 1986) and occupational therapists “frequently find themselves involved in the assessment of their older client's capacity to continue with community living” (Moats, 2006, p. 107). The intense focus on occupation that is required by this process means that occupational therapists have a key role in understanding and determining how autonomy is defined for the older adult population.

Within occupational therapy, autonomy or self-determination is held as a valued concept (Ekelund et al, 2014) that is key to how participation in occupation is experienced. Wright-St Clair and Seedhouse (2005) state, “occupation-focused practice is concerned with enabling people as autonomous persons, and not simply acknowledging their right to make autonomous choices” (p. 22). This understanding of autonomy also informs the manner in which client centred practice in occupational therapy is implemented (Hemmingsson & Jonsson, 2005). Client centred practice is one of the fundamental tenets of the profession and the World Federation of Occupational Therapists (WFOT) states that, “occupational therapy is a client centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in activities of everyday life” (World Federation of Occupational Therapy, 2012, Para 1).

One of the more complex areas where autonomy is at stake is when mental capacity is questioned. Many people with dementia continue to have capacity for some level of autonomy and independence throughout a large part of the illness, but often it is assumed this is not the case. This may

be caused by a lack of clarity about the legal definition of capacity, which is defined as:

The ability, capability, or fitness to do something; a legal right, power, or competency to perform some act. An ability to comprehend both the nature and consequences of one's acts (West's Encyclopedia of American Law, 2008).

Capacity therefore relates to soundness of mind and to an intelligent understanding and perception of one's actions. In law it is defined in terms of legal relations and the capacity to dispose of property by will as the person sees fit (West's Encyclopedia of American Law, 2008). The law states "every person shall be presumed, until the contrary is proved, to have the capacity ...to understand the nature and to foresee the consequences of decisions in respect of matters" (Perkins, 2013, p. 239).

However, the subtleties necessary to understand legal mental capacity are often overlooked in the application of a 'status approach' regardless of the decision to be made, the individual patient's circumstances and the context" (Mujic, 2009, p. 734). The status approach is frequently criticised for the manner in which an entire class (e.g. those with dementia) is assumed to lack capacity. Research indicates that the assumption of mental incompetence means that occupational therapists tend to focus on the occupations the client is no longer safe to do (rather than what the person remains able to do). This kind of negative focus can potentially lead to a perspective that assumes institutional placement is the best and only possibility (Moats, 2007).

Clinical decision-making is often a complex and problematic process (Reich et al, 1998). Little is known

about how occupational therapists think about risk and advocate for autonomy when their clinical decision-making is challenged by the issues that arise around older adults with dementia. This understanding is necessary in order to fulfil the social justice agenda to challenge and extend the capacity of occupational therapist to defend the rights of people with dementia to the fullest possible expression of autonomy. This study seeks to investigate how occupational therapists in general health settings understand autonomy when making placement decisions for people with dementia.

Methods

A qualitative descriptive (QD) method was used (Sandelowski, 2000). Ethics approval was gained from Otago Polytechnic and Māori consultation was completed with both the Polytechnic and the DHB. Purposive sampling was used (Creswell, 2007) to recruit participants from adult general health services.

Six occupational therapists were interviewed for the study; all therapists were community based general health therapists and were female. All six participants identified as New Zealand European, Pākehā. A homogenous sample of community therapists were targeted as these therapists tend to be involved in making placement decisions for those people already living in a community setting.

Those who participated were all highly experienced, with occupational therapy careers ranging from 9 to 30 years, however their experience of working with dementia was more restricted.

Table 1: Participant demographics

Participant	Gender/ Ethnicity	Interview format	Clinical setting currently work	Years of clinical experience	Years of experience working with dementia
1 Lizzi	Female/ NZ European	Face-to-face	Community rehab	Over 30 years	2-3 years
2 Wendy	Female/ NZ European	Telephone	Community rehab	21 years	5-6 years
3 Kristy	Female/ NZ European	Telephone	Community rehab	13 years	Less than 1 year
4 Sarah	Female/ NZ European	Telephone	Community rehab	30 years	On and off over 30 years
5 Claire	Female/ NZ European	Face-to-face	Community rehab	9-10 years	Less than 2 years
6 Sophie	Female/ NZ European	Telephone	Community rehab	17-18 years	3 years

Participants were offered a choice of telephone or face-to-face interview; four of the interviews took place over the telephone, two were face-to-face interviews.

This project required high levels of reflexivity and rigour was attained through processes of member checking, debriefing sessions, and use of a reflective journal.

Results

The findings have been organised into the following themes which have evolved with the research question in mind: a) The meaning of autonomy, including: the ways that occupational therapists define autonomy in relation to client centred practice and how they define issues of capacity and

competence; b) Clinical reasoning about autonomy: how occupational therapists approach autonomy in their clinical reasoning process, how they see patients as having the right to make their own decisions, the time it takes to do assessments that take autonomy into account, the ways that they think about situations where they have to go against the will of the patient, and how they conceptualise the relationship between safety and autonomy; c) The meaning of dementia in terms of capacity for autonomy and the difficulties that occupational therapists have in making judgements about this; it takes resources to make autonomy happen: the lack of resources among therapists and other care workers in terms of time and skills; d) The different perspectives of autonomy: families tend to think about autonomy with different reasoning in relation to placement.

Verbatim quotes from transcripts have been used to illustrate theme categories and pseudonyms have been used throughout to protect the privacy of participants.

The meaning of autonomy

Autonomy is an important concept in bioethical discourse, but it seemed important to get a baseline understanding of how it was actually defined by occupational therapists in practice. Therapists held a basic understanding of autonomy and were in general agreement that it referred to a person's right to make decisions regarding their life, though sometimes they seem to have some doubts about their own understanding. Definitions of autonomy included:

So my understanding of autonomy...I have to scratch back...but it's around the persons right to decide and to choose what's best for them, yeah I think I've got that right (Claire).

In fact, autonomy was a relatively clear theoretical concept to therapists and they recognised that there were significant challenges related to the concept once patients were engaged in the medical system. One therapist described how the autonomy of any individual is challenged as soon as they become a patient.

Patient autonomy, I think it's very difficult right from the beginning when anybody first become a patient. I feel they're undermined just by being a patient. I think just by being a patient you are the weaker player in the dynamic of that relationship, between you and the health professional (Wendy).

This undermining of the patient, of course, is the very reason why patient autonomy is considered to be such a central concept to clinical practice. It was interesting to note that in considering autonomy occupational therapists immediately identified issues related to power and control (the patient is the "weaker player", and is "undermined by being a patient").

Therapists seemed to be aware of the dangers associated with a diagnosis of dementia. Kristy alluded to the effects of stigma related to the diagnosis and how this might impact on the level of autonomy expected.

Everyone has a preconceived idea of what a diagnosis of dementia means and what that then means in terms of supporting those people (Kristy).

There are significant contextual factors in the ways that people are able to experience autonomy. Therapists reported that a person's sense of autonomy could be influenced by family, neighbours or involved agencies such as Housing New Zealand.

I believe that people have a right to live their lives how they want to live them, and that goes across all fields and all people. Rights are certainly compromised by how it affects other people – totally! So it's not just about them (Lizzi).

Occupational therapists identified that their role in supporting autonomy included ensuring the patient has all the information required to enable informed decision-making.

I guess autonomy is about being able to make choices and decisions for yourself and I think we have a role in helping people have all the information so that they can make an informed decision that leads them to be able to be autonomous (Kristy).

Patient age was considered as a possible factor that might impact on therapist's capacity to facilitate autonomy. However therapists were not in agreement about the role of patient age in their ability to support a person's right to autonomy. It seemed easier for some therapists to support autonomy with older people, possibly because they had already established identity and a sense of authority in their lives.

I think it's easier with the older people for them to maintain their autonomy; well it is for me (Sarah).

There can be an assumption that patient autonomy and client centred practice (CCP) is the same thing. There is a belief that CCP has been a key feature of occupational therapy for so many years that it must be central to patient autonomy, yet the relationship between autonomy and CCP is not as clear as it might seem. In fact, the ways that CCP was described in this context seemed to be less about the autonomy of the individual patient and more a way of representing the family as much as the patient. Therapists acknowledged the blurred boundaries around the relationship between autonomy and CCP. In spite of the preponderance of the term in the literature it seems that

some therapists are more comfortable with the term autonomy than CCP.

Everyone having a different understanding of what it (CCP) means. The other part is everyone having a different priority of the importance of it...my idea of autonomy is much clearer in my head than what client centred practice is. I feel client centred practice is a term that is used but not really understood (Sophie).

A key issue was described by Lizzi, who indicated that CCP could in fact mean that her practice is centred on several people and this highlights the tensions around considering autonomy of the older adult.

Client centred is fine but actually is it also very much about mum's needs, is it also about the caregiver's needs. Yeah, what do they need as well, because they're part of the package, and sometimes it's not just one person, it can be several people that it's got to be centred around. It isn't just about the client all the time, you have to think about the other issues that come in there as well (Lizzi).

However there is a potential solution to enabling the voice of the person to be carried throughout the dementia illness. Sarah discussed the importance of early diagnosis and advanced care planning (ACP).

I think as people progress through the disease they lose their voice and I think that if people do get the early diagnosis and they've got ACP it's always there (Sarah).

Therapists clearly indicated a nuanced understanding of how autonomy would play out throughout the course of the illness, and also through different activities. A characteristic of the occupational therapists in general was the agreement that capacity was not a global status but determined in relation to a particular function.

I think well everybody has got some capacity to make decisions (Lizzi).

As you know capacity is determined in relation to particular activities (Wendy).

Clinical reasoning about autonomy

With the placement decision-making process there are complex narrative clinical reasoning processes used – and these include significant factors that can erode the clients narrative within the decision making process. Therapists described a diagnosis of dementia as presenting significant challenge to their ability to support that person's right to autonomy. The main issue with this was about whether the

individual is capable of making an informed decision, a concept that is very important in terms of autonomy.

You're wanting to respect and give them the ability to exercise their autonomy but you're also, all the time, trying to make an assessment as to whether they have the cognitive faculties to make an informed decision (Wendy).

In practice, occupational therapists describe having to make decisions about capacity based on their understanding of function and environment. Therapists were able to distinguish between two kinds of errors that the patient might make: the first about cognitive capacity, the second about the kinds of errors that anyone might be prone to. All therapists described cognitive ability in relation to the person's decision-making. A poor decision is a way of thinking that any individual is prone to, whereas difficulty understanding and considering information is associated with cognitive capacity.

Is this that they're making a poor decision or is this that they can't weigh things up? (Claire).

Therapists described struggling with patients "poor" decision-making. They were very clear about the challenge associated with the fact that they disagreed with what the patient wanted at times.

People's right to make decisions doesn't mean that they make the right decisions or they make decisions that you would make or that they make decisions that fit in with what lots of people would think (Claire).

Issues related to risk and patient safety arose regularly in conversations about dementia. Some therapists had difficulty defining the meaning of the term "unsafe" and it became clear that being unsafe meant quite different things to different therapists. For Sophie being unsafe meant the person being nutritionally compromised or being in distress. Sarah acknowledged that is often a judgement call.

Often it becomes a judgement thing...so it really is when people get quite unwell (Sarah).

Claire reinforced that quite often it varies according to the judgement of the therapist and for her it had changed with years of clinical experience.

When there is imminent risk and I guess that risk would be of harm to them...but I guess for me that's shifted a bit over the years...definitely with experience (Claire).

Kristy reinforced this idea and indicated that this is something that therapists reflect upon during supervision with a senior colleague.

You know when I supervise other OT's, its something that people struggle with in terms of people making decisions that we don't think are great or that it's the best decision (Kristy).

It was also important to participants that they were convinced there had been an adequate assessment period.

I think it's really, really making sure that you've had a really, really robust assessment period and time (Wendy).

However, when it came to working with people with dementia therapists agreed that time to build rapport and establish a comprehensive picture of a person's managing was particularly essential.

I like to think I take time, getting to know them as a person, rather than coming to a quick judgement about, you know, what they can and can't do (Wendy).

Patient autonomy appeared easier to talk about than to bring about in practice. There are times when autonomy can be experienced as a serious inconvenience to all concerned, including the therapist. For example, when what the patient wishes for may be in direct conflict with what the therapist sees as being in their best interest. It seems difficult to avoid being paternalistic in such situations. Therapists seemed to be relatively unconscious of the paternalistic underpinning in this kind of statement, or the degree of power and control that might be associated with such a position.

As clinicians we often want to work with what the client wants but sometimes we actually can't go that way, and it might be detrimental to what they're doing or we might not actually agree that it's the best course of action (Lizzi).

It was interesting that issues related to power and control can arise from the very fact that the therapist has somehow been introduced as a factor into the patient's world. The issue of autonomy therefore surfaced from the initial point of contact. Claire described the dilemma of intervention being provided despite a person with dementia not really wanting the input.

When you feel like you're intruding in somebody's world and they're really not keen for you to be there but you feel like you have to do a job, you have to answer a question for example. That can sometimes be a bit challenging (Claire).

Therapists described a number of case examples where patients were placed against their wishes; in the majority of cases capacity status remained unclear. In these stories therapists found ways of justifying the power and control

issues. The therapists generally had an idea of safety as a bottom line, and the point at which issues of autonomy seemed to no longer feature in their reasoning.

Then that person may have to go into placement, because it may then become too unsafe for them to manage...when somebody gets to a very end point, where despite having good high support in place, they are still not remaining safe and able to manage at home...then I think that's when the decision is there, it's very clear and it's there (Lizzi).

The overall impression from the interviews seemed to be that the combination of lack of experience, lack of choice and time pressure combined to mean that there was a tendency towards safety and away from autonomy when therapists were making decisions for and with this client group.

With busy health professionals wanting to rush things through that it's easy to just err on the side of safety all the time (Wendy).

Erring on the side of safety is less complex than taking risks, and this is also associated with taking less therapy time. However, therapists also highlighted the importance of patient choice in the placement decision-making process and this participant was prepared to put safety as a secondary consideration to this.

For me the key one is actually their choice and where they get their enjoyment for life and what their priority is, and I think safety is secondary in it (Sophie).

It takes resources to make autonomy happen

A key finding was the way that limited resources could lead to a lack of time and skill necessary to ensure that autonomy for people with dementia was a primary consideration. Service change at the district health board (DHB) meant that the therapists interviewed were required to work with people who had a mild to moderate dementia, and for most of the participants, dementia was not a clinical area of passion or even an area of particular interest. The therapists new to working with people with dementia commented that they had received no formal training or support as they commenced this work and as such were required to learn on the job. This was identified as a challenge by a number of therapists.

I didn't have the experience behind me that other people did and I felt a bit out of my depth (Lizzi).

Participants were in agreement that people with dementia require a more specialist type of support. An example was

given how older people will say that they're fine when asked if they wanted help. Acceding to the patient's wishes in this instance seemed to be associated with a skewed idea of autonomy, which could potentially be used as a mechanism for abuse in the form of providing a minimal service.

The people with dementia, their needs are quite specific and if somebody knocks on the door in the mornings to say "I'm here to give you a shower" and the person says "oh I'm fine" and the caregiver then says "ok then see you tomorrow," well we know that's not how it works (Sarah).

Unfortunately poor access to the required formal support was identified as a crucial determinant of placement by participants, regardless of the wishes of people with dementia.

So you might have somebody who is able to do a lot of daily routine, with support and someone to oversee that, but if that's not available and that's not in place then that person may have to go into placement (Lizzi).

The different perspectives on patient autonomy

It seemed difficult at times to understand how therapists could form an unbiased opinion in weighing up information. Some of this information comes from articulate and responsible adults in the middles of their lives; the other part of the dialogue is carried out with someone who has very little power and control in the situation and increasingly a loss of their cognitive capacity. Therapists were well aware of the vulnerability of the individual with dementia in such situations. Claire highlighted family involvement as potentially problematic in relation to patient autonomy regarding placement decision-making.

I guess the challenges often, I find are the biggest when there's maybe differences of opinion, for example if somebody wants to stay at home and their family are really anxious and just want them to be looked after (Claire).

Wendy went on to highlight how problematic family can be in terms of autonomy.

With relatives I feel that you have to be careful that there isn't a hidden agenda, that, you know, before you know it, they've already arranged for the house to be sold, the car to go to whoever, they've looked around facilities and all that (Wendy).

It was obvious to Wendy that family could potentially influence her professional capacity to make an independent decision about what was best for the individual with dementia.

I feel the biggest struggle for me, something I like to keep in mind is their autonomy, you know...so not taking on board information that might have been coloured by relationships and loyalty to other family members (Wendy).

Conversely therapists also described situations where the needs of the family seemed as important as the patient. However patient consent in such crisis situations was not clear.

Sometimes we get involved with people when it's a little bit more of a crisis point and family and relatives are wanting to move things on very, very quickly and they have a lot of historical evidence and stuff about all these behaviours and difficulties they perceive (Wendy).

Kristy reinforced this idea whilst clarifying that placement decision-making is not always about patient need. This is a reminder of some of the debates about the distinction between client centred practice and patient autonomy.

I guess being clear about the need for that, and whose needs you're addressing in terms of whether it's the individual or whether it's the spouses or other family members, be it siblings, children or grand children (Kristy).

Therapists were asked about working with people from different cultures (e.g. Māori) Thinking through hypothetical cultural issues seemed to give considerable insight into therapists thinking about autonomy in general

In some cultures it's expected that the children will look after the elders and that those decisions sort of fall to the children automatically. Autonomy can get really confused because, even without a diagnosis, would they still be expected to be making those decisions or if they were just getting older you know, would they just sort of get taken into that family group and no longer be expected to be making those decisions anyway (Kristy).

Discussion

As a health service, it must be recognised that older adults have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life. Making lives meaningful in old age is not new. What is new is the number of people requiring assessment and intervention and the practice tensions that channel decision making into safety mode, thereby impeding focus on autonomy. This means that there is a renewed challenge to occupational therapists to intervene with compassion and imagination, and to grow the capacity

for ethical reasoning in ways that are congruent with the profession's focus on occupation.

Change is urgently required in New Zealand health organisations in order to better support all health professionals working in dementia care; to prepare a generation of experts capable of meeting the demands of an aging population and to improve the quality of health service being delivered to older adults and the psychogeriatric population. This is reinforced by Pizzi and Smith (2010) who state that, "care needs to be taken to be more creative and effective in developing intervention programs to encourage successful aging...to develop effective programs...to train a whole new generation of experts" (p. 465). Pizzi and Smith (2010) go on to state that, "it is incumbent upon the profession of occupational therapy to continue to become more sensitive to diversity and diverse needs of a growing older population in order to best serve them" (p. 455).

The task ahead is not only to ensure health and survival but also to enable well-being, and well-being is about the reasons one wishes to be alive (Gawande, 2014). This is an important area for the occupational therapy profession to have a real influence on quality of life; it has never been more important or necessary to find a way to change and structure the thinking of therapists around dementia care, Wright-St Clair (2008) states, "New Zealand's aging population presents the opportunity to gain new understandings about being meaningfully occupied throughout life" (p. 14).

There is a paucity of research around occupational therapists understanding and value of patient autonomy. This is surprising given the fact that such principles are central to the philosophy of the profession. Ekelund and colleagues (2014) state, "within occupational therapy self determination is central and included in the ethical code" (p. 116).

The findings of the study have highlighted a need for a more nuanced understanding of autonomy in occupational therapy practice. Despite therapists having a theoretical understanding of autonomy, there are significant barriers to effective practical implementation for people with dementia.

Recommendations from the study include: the need to examine barriers to implementation of National Government strategies (e.g. The New Zealand Dementia Framework, 2013); relevant support and education to be provided to the dementia workforce; a more constructive and proactive use of the medical capacity assessment (e.g. to inform all involved of the rights of the person) to be promoted; improved access to skilled formal support; the development of a clinical reasoning pathway around the placement decision-making process and training in ethical reasoning so

that occupational therapists are better equipped to think through the complex issues involved.

Suggestions for further research include: further examination of the relationship between CCP and traditional ethical concepts; a study of autonomy of the individual with mild/moderate dementia from the perspective of the whole team when making placement decisions; a study from the perspective of OTs working in an inpatient setting; a person with dementia's perspective of autonomy.

Qualitative research does not aim to make generalizations about large populations, but to explore how individuals understand a phenomenon (Creswell, 2007). However (based on clinical experience and national dementia project work) the researcher would argue that the work context and sample used are typical of the occupational therapy dementia workforce of many DHBs around New Zealand, this supports a transferability of the results.

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