

Enabling Occupation at End of Life: A Literature Review

“You matter because you are you. You matter to the last moment of your life”

(Dame Cicely Saunders cited in Royal College of General Practitioners and Royal College of Nursing 2012)

ABSTRACT

Objectives: Occupation, or meaningful activity, can contribute to the wellbeing and quality of life of all individuals. It is therefore a logical tautology that occupation should be enabled for those at end of life. This review examines current provision of these processes by Occupational Therapists, who can be much valued members of palliative teams.

Methods: Following a literature search and critical selection, 10 global papers were identified examining occupation and occupational therapy at end of life; in acute, hospice and community environments.

Results: Universally there appeared a dearth of therapists working in end of life care. Palliative provision in hospitals was found to be compensatory or rehabilitative. Hospice therapy emerged as pleasingly occupational, though the number of hospice places disappointingly few. Community literature was sparse and therefore it proved challenging to draw definitive conclusions. Promising research refracted light on occupation at home, however, there also revealed stretched domiciliary services, wherein clients were ill-informed about the potential scope of occupational therapy.

Significance of Results: A ‘good death’ involving a quality end of life experience is the foundation goal overarching all therapy, medicine and care in palliative provision. Arguably, an occupation-focused approach provided by therapists, meets client needs to enable meaningful experiences in the time available. Current occupational therapy practice environments are not necessarily commensurate in achieving these goals.

There is need to promote the role of occupational therapy and circumscribe what therapists can offer. There necessitates further research across all environments and future funding for therapist positions in palliative teams.

End of life care can be complex and challenging however, therapists can facilitate fulfilment of client-centred occupational goals. In engaging with personally constructed nuances of meaning, quality of life can be raised in those deserving of a significant and emotionally rich daily existence in their final days.

KEYWORDS: Occupation, Occupational Therapy, End of Life, Meaning, Quality of Life

INTRODUCTION

Across all people of every nation, death is a phenomenon common to us all (Benthall & Holmes, 2011). In England, 500,000 people, predominantly older, die every year (Department of Health, 2008), reaching the end of their life journey. The United Kingdom has an ageing population and a growing need for palliative services to care for those who are terminally ill (Kealey & McIntyre, 2005).

Indeed end of life care is both current and pertinent in today's socio political climate. The drive for high quality care, choice and control in Britain, emphasized in the 2008 End of Life Care Strategy and 2011 National Cancer Strategy are reflected and mirrored in the philosophy and paradigm presented by the UK government's white paper; Equity and Excellence (Department of Health, 2010) and the new development programme; Improving Quality (National Health Service, 2014). That patients should be supported, informed and respected is prominent in the agendas of the British National Health Service (National Health Service, 2012) and Department of Health (National Institute Clinical Excellence, 2004 & 2011). Over-arching all aspects of care; people wish to be treated with dignity and have a good quality of life (Department of Health, 2008).

To have a life threatening illness is to be expected to die and to have a prognosis of 6 months or less to live (Hospice Task Force, 1987 cited in Lyons et al., 2002). The time elapse for the purpose of this review is potentially more flexible than this definition suggests, however the imperative tenet is that such individuals are beyond the reach of curative medicine (Benthall & Holmes, 2011). End of life care is the preferred modern term for the assessment, treatment and engagement of those with such a prognosis (National Council for Palliative Care, 2014). Traditionally termed palliative care, the goal of such interventions was to leave the individual free from distress and suffering in the time they had available (National Institute Clinical Excellence, 2004).

Being free from suffering and distress is ultimately the foundational goal with every client of the Occupational Therapist who is arguably well placed to work with this client group having both

generic core skills required, alongside specialist knowledge of occupational interventions (Hagedorn, 2000). Occupational Therapists are concerned with enabling occupations to empower people to embrace positive identities, roles, aspirations and relationships; with others, with their environment and importantly, with themselves (Duncan, 2011).

There are multiple definitions of occupation available, for the purpose of this review, occupation is described in a broad context as a purposeful activity that a person needs, wants or is obliged to do, to live well as a valued citizen. Unlike tasks, which are purely functional and provide no significance or fulfilment for an individual, occupations are embedded in socio-cultural contexts as people choose to perform chosen activities alone, with loved ones, or in groups, in ways which are personally meaningful, spiritually enriching or culturally appropriate. It is important to understand that what one finds valued, another may disregard, as an occupation is a relative concept, which is subjectively self-defined. The imperative to therefore work within a client-centred framework becomes pressingly apparent. There is a time and place to each occupation, which necessarily requires energies, tools, skills or resources to perform (Wilcock, 2006 cited in Park Lala & Kinsella, 2011; Christiansen & Townsend, 2011). Occupation should, in accordance with current professional paradigms in the field, be at the centre of practice, theory and philosophy for Occupational Therapists and is recognised and evidenced as contributing to quality of life of individuals, groups and communities (Finlay, 2004; Wilcock, 2007; Christiansen & Townsend, 2011).

That occupation should be enabled for those at end of life, in all environments, is intuitively, a philosophical tautology (Jacques & Hasselkus, 2004). However, from a theoretical perspective there is a paucity of literature on the occupational needs and facilitation of this client group (Park Lala & Kinsella, 2011). All healthcare professionals, including Occupational Therapists require a healthy evidence base on which to lay their practice foundations (College Occupational Therapy, 2011a). The purpose of this review converges on analysing and synthesising the literature to date thus providing clarity and direction for future research and service provision. Focused ideally on work in

the UK, the dearth of home-grown articles has led this critical review to expand its reach and explore worldwide papers examining occupation at end of life, whilst still ultimately converging attention on British practice and palliative provision. However, there is hope that findings may prove relevant and indeed illuminating for global discourse across multiple disciplines.

METHODS

A traditional narrative literature search was conducted in January 2014 exploring Cinahl, Biomed, Psych Info and Medline medical scientific databases for appropriate articles (McMasters University, 2014). Manual searching was also undertaken at strategic points. Key terms utilised during the enquiry included “end of life”, palliative, terminal*, “cancer care”, dying, occupation* and “occupational therapy”. However, primary search methodology focused on carefully chosen subject terms, alongside keyword parameters, to ensure relevance, comprehensive investigation and consequential appropriation of the literature (University of Illinois at Chicago, 2014). Duplicates were removed as judicious to the procedure.

Literature covering paediatric topics, written before 1995, presented in non-academic journals, scribed in a foreign language, focused on extraneous professions not involving occupational therapy or irrelevant to the aims of this review, were excluded. In addition, a number of articles, although congruent with the subject matter, were found to be inaccessible.

At this stage 27 papers were found. Due to considerations of scope and scale, 3 studies examining end of life care in residential nursing homes, alongside specialist cancer or palliative care centres were eliminated. Due to a paucity of holistic perspective, a further 4 disseminations looking at a specific occupational intervention were precluded from further examination. 1 article exploring survival rather than palliation was also rejected.

Inclusion criteria required literature to be posited in a peer reviewed journal and to be fully published at the time of investigation (Bennett & Bennett, 2000). Through this process the findings

were ultimately supplemented with studies looking at adult and older adult populations who have a terminal life-limiting illness not restricted to oncological diseases.

Further scrutiny was then conducted on the prevailing literature to determine the quality of research evidence presented and the potential potency of the articles for this review (Bennett & Bennett, 2000). 8 opinion pieces were excluded from critique alongside 1 case study which did not meet the advisable level of evidential strength required. Whilst practice examples were not immediately precluded, care was taken to ensure rigor and prudence in their selection in order that considerable bias and weakness were eliminated as far as possible. For any review a minimum level of veracity requires examining in considering the suitability of literature that sits poorly in any hierarchy of evidence (Petticrew & Roberts, 2003; University of Oxford, 2009; Tomlin & Borgetto, 2011).

Following selection processes 10 papers were revealed that met the inclusion criteria; these documents are delineated in table 1.

RESULTS

End of Life Care in the Acute Hospital

One British study surveying the terminally ill revealed that only 0.76% of a sample of 132 participants expressed a desire to die in hospital (Squire, 2011). This is starkly contrasted with statistics illustrating that 58% of deaths in the UK actually occur in acute environments (Department of Health, 2008). Pertinent for this review is the transpiration that large numbers of palliative patients are resident in hospitals and are indeed dying in hospitals. The importance of ensuring a good quality of life and a dignified death in this setting becomes paramount (Field & Cassel, 1997 cited in Pizzi, 2010). Consequently, this provides ample justification to launch research at this promontory and evaluate current practice in the acute environment.

5 articles were obtained that focused, at least in part, on hospital settings.

Discharge Planning

Two Australian studies questioned whether there was enough Occupational Therapist input for increasing service requirements. The censuses in each piece of research unfortunately contained abstruse methodologies, uncertain sampling and unclear statistics (Halkett et al., 2010; Keesing & Rosenwax, 2011). Whilst supporting the notion of a workforce deficit the resulting numbers cannot perhaps be said to be demonstrative of the actual professional population.

However, findings from each of these papers have great utility for this study in potentially revealing the work and opinions of therapists in acute settings (in Oceania at least). Health professionals (Halkett et al., 2010) and carers (Keesing & Rosenwax, 2011) saw therapists' work as a few home visits alongside prescription of aids and equipment. Therapists in both surveys acknowledged their role in discharge planning but felt themselves capable of so much more. What transcends in both articles is a widespread dissatisfaction with occupational therapy services that are inadequate, disenfranchising and unduly lacking in occupation-focus. This has implications for all professionals working in end of life care and clearly signifies needs are going unmet.

If Occupational Therapists are not in progressive posts in end of life settings, enabling occupation and facilitating a meaningful life of significant activities, if not impossible becomes intangible. Nevertheless, it would be convenient to purport that the problem is an entirely Australian phenomenon where therapists are limited to reductionist work in a few acute hospitals throughout disparate regions. Undoubtedly, the generalisability of parochial opinion tests, and even workforce censuses, focalized to a specific area, must be challenged and explored.

Squire (2011) writes for a European audience on a UK pilot project, circumscribing an Occupational Therapist's work in a hospital MDT. Evidently, she writes of a similar shortage of occupational therapy services in end of life care, which suggests that therapy deficits are a global and also British issue.

Squire writes her paper from within a medical model and talks of therapists enabling mobility and function and not occupation that is meaningful to the individual (Law et al., 1997 cited in Jacques & Hasselkus, 2004). Whilst promoting the value of the Occupational Therapist in the MDT is much welcome, it is perhaps a little disappointing that the presented role of the therapist is once again of discharge planning to expediate cost and prevent patient readmission (Boatang, 1998 cited in Kealey & McIntyre, 2005). Acute services seem in need of a paradigm shift to engage in work that acknowledges the holistic needs of the person and the eclectic skills of the practitioner (Wilcock, 1998).

Rehabilitation

Over the Atlantic, two authors write of rehabilitation goals for Occupational Therapists in end of life care. Their statistics suggest that end of life care is more progressive in North America whilst the number of employed therapists still falls short of service needs.

Some authors question the appropriateness of rehabilitation in the field (Benthall & Holmes, 2011; Park Lala & Kinsella, 2011) and yet many interventions operationalised appear to have a rehabilitative focus and many authors promote the contribution of rehabilitation to the domain of palliative care (Kealey & McIntyre, 2005). Both Schleinich et al (2008) and Kasven-Gonzalez et al (2010) argue that rehabilitation is over-looked for the terminally ill.

Whilst historically rehabilitation potentially adds to the therapist's repertoire of treatment options and is more holistic than a purely compensatory (equipment) model, it is arguably still reductionist and in being so a quantum away from the meaningful occupational practice that is so desirable (Benthall & Holmes, 2011).

End of Life Care in the Hospice

On discharge from acute hospitals patients are sometimes fortunate enough to gain access to hospice services. The hospice movement has grown primarily from cancer care in the late 20th

century (Pizzi, 2010) into the holistic centres serving multiple client groups that are apparent today (National Hospice Palliative Care Organisation, 2014).

Despite just 4% of the palliative population dying in hospices (Department of Health, 2008), the literature grounded in these settings and ideals is some of the richest and most prevalent in the occupational therapy evidence base. It would therefore be inexpedient to disregard this area of research and not explore what hospices can offer to practitioners working with the terminally ill.

3 papers were selected to examine practice occurring in hospices.

An Occupational End of Life Narrative

Pizzi's American hospice case study (2010) attempts to exemplify the positive impact that working occupationally can have on an individual who is terminally ill. Not without an element of conceptual antithesis the piece is centred on improving quality of life through lived experience of occupation.

The primary contention with Pizzi's work is not with his ideals or occupational paradigm but with the strength of his evidence and the character of his writing. Whilst purporting powerful messages about enabling occupation and consequential quality of life, some might argue that Pizzi is not critical enough and relies too heavily on reproducing quoted expert opinion (Whalley-Hammell, 2009).

Occupations in the Hospice

However, in defence of Pizzi's philosophical stance are Lyons et al (2002) and Jacques and Hasselkus' (2004) corroborating studies exploring occupation in the hospice. Each qualitative design takes a unique angle on capturing the occupational experiences of attendees in order to better understand occupation at end of life.

Whilst some may question the value of contributing subjective, qualitative research papers to a scientific evidence base, I would argue that qualitative studies justifiably deserve their place in research as client-centred papers (Whalley-Hammell, 2001) rich texts conveying experiences the reader can find plausible and relative, thus strengthening understanding of phenomenon (Glassman & Hadad, 2009; Park Lala & Kinsella, 2011) and useful exploratory tools into how services can work for people (Pettigrew and Roberts, 2003).

Arguably, these two papers have contributed qualitative research of significant quality to the discourse from which we can glean the importance of the hospice movement in end of life care, which appears to be progressive and occupationally focused in their daily operation.

To each study results there is an existential and transcendent temporal element, focusing on unique and personal occupation in the past, present and future. There is a bifurcated purpose to occupational moments that offer a spiritual dimension to people, converging on living and dying in equal measure. These aspects are mirrored in other literature (Bye, 1998 cited in Kealey & McIntyre, 2005; Benthall & Holmes, 2011) and further substantiated by Park Lala & Kinsella's phenomenological community study (2011).

There are also underlying themes found in all of these papers of contributing with others in families and communities, preparing and adapting for change and continuing to appreciate everyday occurrences through occupation. Special and mundane activities are reinterpreted and given new significance in the context of the life limiting illness (Lyons et al., 2002; Jacques & Hasselkus, 2004; Park Lala & Kinsella, 2011). There are echoes of needs to complete occupations, dreams, meetings and rituals that are meaningful to the individual (Park Lala & Kinsella 2011). The giving of tokens, gifts and handmade items was recurrent throughout.

In attempting to explicate occupation at end of life, professionals are better placed to understand occupational needs and enable positive, meaningful occupational experiences for those who are dying (Wilcock, 1998; Benthall & Holmes, 2011).

End of Life Care in the Community

There is a paucity of literature contextualising end of life care in the home environment and yet domiciliary care in the community has been developing in more recent years representing a desired shift away from palliative treatment in institutions (Kealey & McIntyre, 2005). Two independent patient and population surveys identified overwhelming desires for people to remain at home at end of life (Kealey & McIntyre 2005; Squire, 2011); this is counterpoised by the dichotomy of government statistics that only 18-25% of people actually achieve this goal (Department of Health, 2008).

Clearly, home care may present some obstacles not least to the families and friends of patients who necessarily assume more responsibilities and duties of care (Kealey & McIntyre, 2005). However, a community service can also provide a wealth of opportunities; to engage in occupation and life within a truly client centred framework, away from clinical environments and medical operations (Park Lala & Kinsella, 2011).

It is these possibilities that are explored in the rare and elusive subsequent 2 articles examining occupation and therapy at home.

Occupation in the Community

In Park Lala and Kinsella's paper (2011), the reader is immersed through the interview transcripts in rich and thick dialogue which captures the essence of what it is to live and die with terminal illness from the perspectives of the dying person. These immanent and yet conversely tangible processes (Priest, 2002) are expressed through an occupational lens which examines 6 themes focused on existential pursuits, accommodation of change and activities which promote positive affect.

If Lyons et al (2002) and Jacques and Hasselkus (2004) dipped their toe into the palliative pool of practise to feel the warmth of occupational engagement in the hospice, Park Lala & Kinsella

(2011) fully submerge the observer in a deeply spiritual plunge into the depths of qualitative inquiry, allowing the ripples of occupation to gently wash over the peruser's metaphorical body. What transpires post-swim is a realisation that to enable holistic, client-centred occupation at end of life is to facilitate meaningful experiences for the individual thus contributing to a good end of life experience. That such occupational engagement can occur at home is both inspirational research and guiding material for future practice.

Weight is subsequently given to the exposition dialogue championing the enablement of occupation in community and indeed all end of life settings. The embodied experiences of participants are pocketed with examples of expressions of joy on engaging in favourite pursuits whilst despair is expressed when valued occupations are prohibited. Interestingly, these findings were mirrored in both qualitative hospice studies, corroborating meat to occupational bones (Lyons et al., 2002; Jacques & Hasselkus, 2004).

Occupational Therapy in the Community

If Park Lala & Kinsella provide us with an admirable ideal for the community Kealey and McIntyre (2005) hope to provide us with an insight of the everyday reality. This is all the more valuable for being cited close to home in the domiciliary settings of Northern Ireland. The study focuses on the evaluation of a home therapy service from the perspective of its clients and carers.

However, in looking at the challenges and importance of various client issues, the study converges attention on symptoms, practical and psychosocial problems. There is no survey of holistic occupational needs or spiritual provision. Quality of life questionnaires focused on end of life care find that existential domains of satisfaction are concordant with overall levels of satisfaction and precedence (Cohen et al., 1995; Cohen et al., 1997; McMillan & Weitzner, 1998), yet this research focuses on functions. Tellingly, professional efforts were directed on equipment, transfers and adaptations with goal achievement being attained by only 15% of service users, thus it

is questionable whether this service is truly meeting client needs. However, what does become clear is that clients and carers don't fully understand what occupational therapy can offer them.

SIGNIFICANCE OF RESULTS

Introduction:

A 'Good Death'

In Canada it has been shown that decreased ability to participate in enjoyable activities influences the decision of some to euthanize (Park Lala & Kinsella, 2011). Conversely, pleasure in occupations and meaningful experiences, solitary and shared; have been illustrated to facilitate an attitude of gratitude and joy, a life worth living (Lyons et al., 2002).

A quality end of life experience may potentially include pain and symptom control (Seymour et al., 2002); research has demonstrated people fear a 'bad death' which has undue anxiety or physical distress (Jacques & Hasselkus, 2004). However, a 'good death' can also involve a sense of control, preparedness, awareness, holism, peace and contribution to others; all conditions that can be furthered through occupation and meaning (Lyons et al., 2002).

Fulfilment of Potential

Life limiting illnesses for a number of reasons can be interpreted by many as difficult and full of progressive loss; loss of functioning, loss of desired activities, loss of energy, loss of roles, loss of hope and morale (Kealey & McIntyre, 2005). Occupational enablement during such challenging times, can conversely and perhaps counter-intuitively, facilitate a person to live, through focusing on desired goals and activities, assisting them to overcome some of the complex obstacles faced, maintaining and developing valuable roles and preserving and raising self-worth, self-identity, self-determination and dignity (Miller-Polgar & Vrkljan, 2001).

What follows from a discussion of the literature is a delineation of the requisite conditions, concepts and skills needed to achieve these aims. For the purpose of clarity and to mirror professional contingents, these themes are divided into philosophy, theory and practice.

Philosophy:

An Occupational Paradigm

We have seen that occupation at end of life is a significant and important phenomenon; however, for every study we have illuminated that explores occupational practice (Lyons et al., 2002; Jacques & Hasselkus, 2004; Pizzi, 2010; Park Lala & Kinsella, 2011) there are apparent therapy articles that do not invest in an occupational paradigm (Schleinich et al., 2008; Kasven-Gonzalez et al., 2010) or discuss prevailing contemporary services that are not meeting occupational needs (Kealey & McIntyre, 2005; Halkett et al., 2010, Keesing & Rosenwax, 2011; Squire, 2011).

Occupation allows individuals at end of life to adapt, cope, reflect, learn, live, do, appreciate, contribute, prioritise and fulfil their potential within the special time they have available (Benthall & Holmes, 2011). For many it can make the difference between ego integrity and ego despair (Glassman & Hadad, 2009) and assist to process the stages of grief associated with the dying process (Kubler-Ross, 1969 cited in Gross, 2005). For the occupational therapy profession, occupation is the medium through which therapists can catalyse positive change in the people they work with, including those at end of life (Trombly Latham, 2002).

Integral to this process is the facilitation of meaning which is arguably transcendent and can promote positive affect to individuals at any life stage (Lyons et al., 2002). When time is restricted as so often is the case (Kealey & McIntyre, 2005) the search for emotional significance becomes all the more pressing (Carstensen et al., 1999).

The definition of occupation in any modern occupational therapy syllabus is recondite without the contribution of meaning for the person (Jarman, 2011). Occupational experiences become

functional tasks or activities without spiritual purpose of direction or pleasurable gain for the participant (American Occupational Therapy Association, 2002 cited in Jacques and Hasselkus, 2004).

In engaging with the complex dimensions of the person, the occupation and the environment, meaning can potentially be founded, promoting wellbeing and quality of life (Law et al., 1996; Strong et al., 1999; Miller-Polgar & Vrkljan, 2001).

Promoting health at end of life is perhaps a contentious objective (VanderPloeg, 2001). Health can be considered in a broad context to encompass an ability to care for self and others and have capacity to make decisions and exercise control (World Health Organisation, 1986 cited in Pizzi, 2010). However, this is arguably not possible in every actuality without redefining the concept of health into an unrecognisable tenet. For those with dementia, cognitive, language, neurological, muscular or vocal difficulties, capacity to care for self or make and communicate decisions may be considerably impaired (Seymour et al., 2002; Papapetropoulos et al., 2007; Alzheimer's Society, 2014; Motor Neurone Disease Association, 2014; National Institute on Aging, 2014; Parkinson's UK, 2014).

Imaginably, for those at end of life, making the most of each and every day and endeavouring to sustain holistic wellbeing (Kealey & McIntyre, 2005), defensibly a subjective (Doble & Santha, 2008) and not absolute term (Huber et al., 2011), is perhaps a more realistic and achievable goal.

Quality of life, defined as experiencing enjoyment, psychological, physical and spiritual acceptance and accord, alongside hope surrounding opportunities and possibilities (Jacques & Hasselkus, 2004) is potentially attainable for all persons regardless of illness progression, age or diagnosis (Pizzi & Briggs, 2004). In line with UK government and professional agendas (National Institute Clinical Excellence, 2004; National Health Service, 2014; World Health Organisation,

2014) promoting quality of life should necessarily be our overarching treatment goal (VanderPloeg, 2001; College Occupational Therapists, 2011b).

However, therapists require an occupational framework from which to cultivate their conceptual ideology, assessments and subsequent interventions. Occupation may not always be health-giving but it can arguably be described politically as a basic human need (Hansen et al., 2007; Stadnyk et al., 2011).

Occupational injustice occurs when an individual is excluded from participation in occupation through circumstances outside their control, extraneous to the limitations or symptoms of their presenting condition. The phenomenon of boredom, loneliness, isolation and a lack of meaningful occupation can be a real existence for those at end of life and can contribute to feelings of helplessness, hopelessness and uselessness (Lyons et al., 2002; Keesing & Rosenwax, 2011). The impact of too little occupation on wellbeing can be devastating (Kealey & McIntyre, 2005) and yet can be steadily overcome through the enablement of occupation (Lyons et al., 2002).

Theory: Core Constructs

A Holistic Approach to Therapy

Palliative care means delivering a holistic approach within end of life services and meeting the physical, psychological, social and spiritual needs of the terminally ill (National Institute Clinical Excellence, 2004; National Health Service, 2005; Meredith, 2010; World Health Organisation, 2014).

Multitudinous physical interventions which are generally well documented and are arguably core to a therapists' repertoire still require viewing through an occupational lens to ensure a truly holistic approach. Kealey & McIntyre (2005) discuss that psychological aspects of care can be difficult to measure and yet are no less important. Concerns have been raised that services, particularly acute, don't adequately identify and address psychological distress and instead focus on purely physical

concerns (Seymour et al., 2002; Terry & Westcott, 2012). Time restraints have been documented as one potential barrier (Kealey & McIntyre, 2005) and yet the importance of positive emotional affect at end of life is already well established.

Social context is additionally relevant for occupations (Kealey & McIntyre, 2005) where the social climate that an individual is consumed can contribute greatly to feelings of belonging and connectedness within the sphere of the people around them (Lyons et al., 2002). Contributing to others was a predominant theme found in the literature which enabled individuals a sense of wellbeing and self esteem (Pizzi, 2010), whilst embracing meaning was found to fundamentally mean embracing spirituality in the lives of the terminally ill (Wilcock, 1998). Spirituality can be religious when practice and reflection is sometimes heightened at end of life (Park Lala & Kinsella, 2011) though for many it is about significance in the time they have available (Wilson, 2010; Benthall & Holmes, 2011).

For the occupational therapist, this is elementary to their discipline (College Occupational Therapists, 2014b) and necessitates offering a flexible programme to fulfil the universal requirements of service users, involving constant assessment of priorities (National Institute Clinical Excellence, 2011), work towards occupational goals and of course, regular benchmarking of progress.

Client-centredness & the independence paradox

Emphasis must focus on self-determined occupation for therapists and teams to work in a truly client-centred fashion (Park Lala & Kinsella, 2011). Attention may not necessarily rest on independence in daily activities of living (Jacques & Hasselkus, 2004). Washing and dressing whilst important for some (Benthall & Holmes, 2011) may hold little significance for others (Pizzi, 2010). Furthermore, functional independence may not be possible at the end stages of life (Kealey & McIntyre, 2005). Indeed many have pointed out that occupational lives can involve a complex

mix of dependence, independence and inter-dependence (Putnam, 2000; Whalley-Hammell, 2009; Iwama, 2011; Bonikowski et al., 2012).

It is perhaps about understanding that individuals make unique choices, have unique needs and unique levels of engagement (Lyons et al., 2002). In remaining holistic, client-centred and occupation-focused, clients may find a locus of control over their end of life goals, at a time when they may be experiencing so many challenges; they may gain opportunities for meaningful engagement (Jacques & Hasselkus, 2004).

Practice: Settings, Services, Core Skills & Interventions

Environments: The Hospital

Illustrated in the requisite appraisal of articles; acute end of life services appear confluent on ideology that focuses on symptoms and functional issues to be solved by professionals. Furthermore, there becomes apparent global frustration and discontent with the lack of occupation-focus in hospital care (Wilding & Whiteford, 2009). Given the large number of persons resident in hospitals at end of life, this is concerning for all invested. The last few decades has seen death sanctioned to the care of medics in acute settings and it seems we are potentially failing those that arrive in these circumstances (Jacques & Hasselkus, 2004).

However, there are some measures to remedy the existing conditions. Academic papers are raising the dialogue regarding reductionist treatment in hospitals (Halkett et al., 2010; Keesing & Rosenwax, 2011) whilst the government paper Improving Quality (National Health Service, 2014) sets out special measures for improving end of life care in acute environments in the UK. Part of this programme involves the enablement of greater choice in end of life setting, to facilitate transfers to hospices and the community and yet sadly, within this mandate, there is still no discussion of holistic, client-centred, goal focused therapy for those remaining in hospital.

Environments: The Hospice

Within the hospice we have observed that occupational practice is operational and fruitful; in direct contraposition to a biomedical system, holistic needs are addressed beyond disease management enhancing quality of life for those who reside within (Jacques & Hasselkus, 2004; National Hospice and Palliative Care Organisation, 2014). Clearly, the role of hospice services to palliative provision is an important cynosure to acknowledge, providing a potential transverse between hospital and home (Lyons et al., 2002) and a place of respite and peace. Nonetheless, the limited capacity of hospice places puts restrictions on the benefits that can be achieved by these institutions.

In the literature reviewed small numbers of people were resident in the hospices with even smaller samples participating in the research. Potentially, it could be posed that these conditions were anomalous findings of unrepresentative studies and yet national British statistics prove otherwise; hospice beds at end of life are in short supply (Department of Health, 2008).

Environments: The Community

The community is at times illustrated to contribute to a greater freedom and ecological authenticity than institutional settings provide. Potentially, it could be postulated this provides the rationale behind patient's wishes to remain at home, alongside pleasure found in privacy, familiarity and comfort (Kealey & McIntyre, 2005). These findings would drive forward the impetus to provide services to meet this need and enable residency and occupation in domiciliary environments, whilst simultaneously forwarding government agendas in this direction (Department of Health, 2008). Unfortunately, as research is limited in this area, the documented extent of success that domiciliary services are achieving in accomplishing these goals is at present unknown.

Bridging the Gaps

What does become apparent under examination of literature is that despite some growth in the sector (Benthall & Holmes, 2011), there is a global paucity of therapists working in palliative care transecting all environments (Squire, 2011). Occupational Therapists are not commissioned

frequently enough in end of life settings and occupation is not accommodated as central tenet in services (Park Lala & Kinsella, 2011). There is prime opportunity for therapists to bridge this occupational gap.

The Person

Arguably, Occupational Therapists are well placed to work in end of life care; through training and the process of professional socialisation, they already possess knowledge that therapeutic relationships underlie all interventions (Hagedorn, 2000). This is never more pertinent and relevant than in the field of palliative care where delivering client centred services aimed at improving quality of life may involve caring, not curing (Meredith, 2010).

The use of compassion, kindness, humour, support and active listening skills are frequently illustrated to form an essential and valued part of therapy (Lyons et al., 2002; Gilbert, 2005) and yet the underground practice of working with distress and suffering is oft neglected in academic dialogue (Park Lala & Kinsella, 2011).

Effective communication is fundamental to forming positive therapeutic relationships with the terminally ill (Kealey & McIntyre, 2005), which have been documented to be as meaningful and significant for some as relationships with loved ones (Jacques & Hasselkus, 2004). Furthermore, both British government (Department of Health, 2000; National Institute Clinical Excellence, 2004; National Health Service, 2005) and professional (College Occupational Therapists, 2011*b*; Health Professions Council, 2013) mandates delineate the importance of good interpersonal skills when engaging with clients. Clearly, working with patients at end of life involves more than just handing out equipment; it involves deploying the entire holistic repertoire of skills an Occupational Therapist possesses to meet complex needs at end of life and understand the “emotional magnitude” of living with a terminal disease (Benthall & Holmes, 2011. p.8).

The Occupations

There are multitudinous skilled interventions used in palliative care by Occupational Therapists, many of which are well represented in professional literature (Lyons et al., 2002; Kealey & McIntyre, 2005; Schleinich et al., 2008; Halkett et al., 2010; Kasven-Gonzalez et al., 2010; Squire, 2010; Keesing & Rosenwax, 2011; Park Lala & Kinsella, 2011). Traditional services include addressing activities of daily living, mobility, equipment and transfers, positioning, seating & comfort, rehabilitation and home assessments. Pain and fatigue management are also essential therapeutic tools of practice that can prove invaluable to clients. Psychological interventions can focus on stress management, relaxation techniques and carer support.

Whilst proficient and effectual contributions; some of these interventions are not promoted and many of these services do not have an occupational focus (Benthall & Holmes, 2011). Additional meaningful activities could be enabled, as directed by client needs, such as creative activities, social engagements, complimentary & restorative therapies, green occupations in nature, trips out, cognitive stimulation or diversion, alongside spiritual reflection, discussion, preparation, philosophical pursuits, delegation of gifts, narratives, family time and life story work (Pizzi, 2010). However, if practitioners do not offer an occupational assessment and service users and carers don't understand the full range of services that can be offered, they cannot be expected to utilise or ask for them (Kealey & McIntyre, 2005).

Philosophy: Promoting the role of occupational therapy

The Uniqueness of Occupational Therapy

There is feasibly a need to promote the role of occupational therapy in end of life care and raise awareness of the potential benefits with the public, commissioners and other practitioners (Squire, 2011).

There is a need to convey to other members of the team what an occupation-focus can bring; without this paradigmatic perspective practitioners risk losing their unique contribution with

medics, nurses, physiotherapists or social workers misunderstanding the therapist role (Keesing & Rosenwax, 2011). What can result is a lack of appropriate referrals, muddy role boundaries and poor inter-disciplinary communication (Wilding & Whiteford, 2009).

Multi-Disciplinary Working

In understanding the occupational therapy role other professionals can utilise it to full advantage and complement the practitioner within the multi-disciplinary team (Kasven-Gonzalez et al., 2010). Reciprocally, therapists can also learn from others (Benthall & Holmes, 2011). In communicating effectively and having clear professional goals there subsequently follows better client outcomes, more productive teams and greater quality services as laid out in professional (College Occupational Therapists, 2011a; College Occupational Therapists, 2011b; Health Professions Council, 2013) and British governmental (National Institute Clinical Excellence, 2004; National Health Service, 2005; Skills for Care, 2012; National Health Service, 2014) guidelines and standards (Kealey & McIntyre, 2005).

Networking in the Wider Community

Indeed efficacious communication and networking is necessary across the broad spectrum of services, individuals, social, spiritual, voluntary and charitable agencies involved in end of life care (Benthall & Holmes, 2011). This ensures seamless transitions between environments and persons, translating continuity of care, connecting the patient with their community and avenues of support (Park Lala & Kinsella, 2011).

Theoretical Foundations: An Occupational Evidence Base

Evidence Based Practice

Fundamentally there is an overwhelming need for every discipline to ensure that care delivered is of optimum quality and interventions carried out are grounded in the best available evidence of worth and effectiveness (Whalley-Hammell, 2001). For all practitioners, this requires a healthy evidence

base on which to balance practice. Occupational Therapists necessarily apply theoretical frameworks and evidence based interventions utilising clinical judgement and professional reasoning (Kuipers & Grice, 2009; Rassafiani et al., 2009; Carrier et al., 2010). However, they primarily need a solid research foundation to facilitate this process.

The End of Life Literature

Squire (2011) and Halkett et al (2010) suggest the occupational therapy profession has an uncertain and poor evidence base but arguably there is growing research supporting the benefits of occupation across a broad spectrum of circumstances (Wilcock, 1998; Finlay, 2004; Wilcock, 1991 & 1993 cited in Jacques & Hasselkus, 2004; Kealey & McIntyre, 2005; Jarman, 2011). Perhaps then the issue lies with the quality of research in end of life care.

This review confirmed that there is a paucity of research accenting focus on occupational therapy and palliative care (Kealey & McIntyre, 2005). The papers available largely constitute opinion pieces and acute articles of questionable rigor. Whilst promising literature was found in both hospice and community settings these occupational paragons were disappointingly few, consisting of a handful of small qualitative studies with an almost complete absence of quantitative scholarship. Studies delineating the scope of occupational enablement, measurement of consistency or efficacy of global services or the empirical determination of quality of life for individuals are simply not present in published work.

In addition, there are noticeably large gaps in the literature for instance a discussion of hospice at home services (National Association for Hospice at Home, 2014) or complementary work within the charitable sector (Macmillan, 2014).

Clearly, holistically, more qualitative literature is required in the field to add to global comprehension concerning how occupation can enrich end of life experiences (Park Lala & Kinsella, 2011). Potentially a meta-ethnography synthesising the qualitative research to date may

also prove prudent alongside new quantitative surveys adding numerical weight to the evidence base. It is in this vector that studies require directing in order that services can be further developed that meet occupational needs (Kealey & McIntyre, 2005).

End of Life Services

Working Practice

Clearly end of life care necessitates working within ethical guidelines and professional boundaries (College Occupational Therapists, 2011a) to deliver a service that meets the needs of its users.

Palliative provision should be readily accessible and prompt; dimensions which have been shown to be important to clients and British government agendas (National Health Service, 2005; Department of Health, 2008) being fundamental to delivering quality care in time sensitive scenarios.

Future Practice

There follows a capacity for service development in end of life care where more funding is required to provide resources and fuel occupational therapy positions in a much needed sector (Keesing & Rosenwax, 2011). In a modern healthcare climate accessing finance is key; governors and practitioners need to understand the nature of the occupational therapy profession, the benefits of an occupational approach, the evidence behind the therapist's interventions and the outcome measures which can demonstrate both quality and progress. Supplementary to this drive for professional understanding, there also requires further research to illustrate the value of occupational therapy practice to the patient communities we serve (Wilding & Whiteford, 2009; Parnell & Wilding, 2010; Park Lala & Kinsella, 2011; College Occupational Therapists, 2014a; Gillen & Greber, 2014).

Limitations

Limitations of this study centre on the circumscribed dearth of literature in this field. Needless to remonstrate, there also features a lack of discussion and research surrounding non-oncological

conditions such as cardio-respiratory failure, gastro-intestinal complications, end stage neurological disorders and terminal illnesses such as motor neurone disease, Huntington's, certain types of muscular dystrophy and multiple system atrophy amongst many other life threatening diseases, which bring their own obstacles and nuances of care (Lyons et al., 2002; National Health Service, 2005). There was also a deliberate filtration of studies exploring palliative care in residential and specialist care units, which would certainly create bias in the findings which might otherwise have examined growing concerns surrounding those with dementia at end of life (Seymour et al., 2002; Alzheimer's Society, 2014). Globally, the lack of large scale, rigorous empirical studies, particularly on home-ground, brings doubt regarding the strength of conclusions drawn and yet of itself is telling of the need for future research. However, it is posed that the richness of qualitative debate unearthed is indeed promise of multitudinous benefits to be gleaned from an occupation-focused practice. Finally, the author unavoidably is tenable to occupational predilection in the preceding review given the occupational nature of their profession and current canon, alongside the process of professional socialisation. However, this arguably does not detract from the findings of the study which are potentially sturdy enough to withstand critical examination and appeal.

Conclusions

The role of occupational therapy in palliative provision is diversified, complex and challenging (Kealey & McIntyre, 2005). End of life care necessarily requires a comparative occupational shift in occupational therapy practice, particularly in acute and community settings. There is a universal need for further research and funding across all environments and necessary education and promotion of the Occupational Therapist's role. Practitioners need to meet and continue to meet professional, governmental, ethical and public expectations of a personal and compassionate end of life service. Above all there requires a recognition of the unique needs of those at end of life, who are time-limited and deserve an enabling, holistic, client-centred practice which enhances dignity and respect in facilitating meaning in life and death.

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Table 1: Characteristics of included studies

Study	Published Date	Setting	Country of Origin of Research	Hierarchy Type Of Evidence/Research Design	Research Strategy	Research Method	Inductive/Deductive Paradigm	Sample Size	Primary Diagnosis	Research Aims
Halkett et al	2010	Predominantly Acute Hospital	Australia	Comparative Cross Sectional Design	Qualitative	Semi-Structured Interviews	Inductive	20	N/A	To question barriers perceived by professionals, which potentially prevent occupational therapy input, in end of life care in Australia.
Keesing & Rosenwax	2011	Predominantly acute hospital with some transection into community contexts.	Australia	Comparative Cross Sectional Design	Illustration Mixed Methods (Preliminarily Quantitative, Priority Qualitative)	E-Mail Survey & Semi-Structured Interviews	Inductive	32	Mixed Diagnosis	To survey the number of therapists working in end of life care in western Australia and to ascertain the opinions of carers and therapists regarding the occupations of the terminally ill and occupational therapy service provision in end of life care
Squire	2011	Acute Hospital	UK (England)	Natural Quasi Experimental Design / Evaluation Research - Longitudinal Cohort Study	Quantitative	Data Collection from Records	Deductive	190	Unknown	To promote, justify and quantify the value of the role of the Occupational Therapist in discharge planning in an acute palliative multi-disciplinary team in the UK.
Kasven-Gonzalez et al	2010	Acute Hospital	USA	Case Study	Qualitative	Participant as Observer of an idiographic exemplifying case	Deductive	1	Cancer	To promote, justify and quantify the value of the role of the Occupational Therapist in discharge planning in an acute palliative multi-disciplinary team in the UK.
Schleinh et al	2008	Acute Hospital	Canada	Cross – Sectional Design / Evaluation Research	Completeness Mixed Methods (Preliminarily and Priority Quantitative)	Structured Interviews	Deductive	32	Cancer	To strengthen the evidence base for rehabilitation in attempting to demarcate and test a standardised assessment based on the Canadian Model of Occupational Performance, for rehabilitation goals in palliative care.
Pizzi	2010	Residential Hospice	USA	Case Study	Qualitative	Participant as Observer of a nomothetic critical case	Deductive	1	AIDS	To promote the value of working occupationally with terminally ill patients to facilitate ‘a good death’.

Jacques & Hasselkus	2004	Residential Hospice	USA	Ethnographic Longitudinal Cross Sectional Design with Case Study Elements	Qualitative	Active Participant Observation of nomothetic and idiographic experiences, Semi structured & In-Depth Interviews, Single Focus Group, Content Analysis of Documents, Field Notes	Inductive	30	Predominantly Cancer	To facilitate better understanding of occupation at end of life by exploring the meaning of occupation for dying patients in a residential hospice in the United States.
Lyons et al	2002	Day Hospice	Australia	Longitudinal Cross Sectional Design with Case Study Elements	Qualitative	Focus groups, Participant Observation & Individual Semi-Structured Interviews	Inductive	23	Cancer	To examine occupation at end of life in day hospice attendees through a doing-being-becoming conceptual framework.
Park Lala & Kinsella	2011	Community	Canada	Phenomenological Methodological Approach to Cross Sectional Research	Qualitative	Semi-Structured Interviews	Inductive	8	Predominantly Cancer	To facilitate better understanding of how quality of life can be raised in the terminally ill, through the lived corporeal experience of occupation at home.
Kealey & McIntyre	2005	Community	UK (Northern Ireland)	Comparative Cross Sectional Evaluation research	Enhancement Mixed Methods (Preliminarily & Priority Quantitative & Qualitative)	Structured Interviews	Inductive	60	Cancer	To inquire what constitutes a quality occupational therapy service in the eyes of its users and far existing palliative provisions in Northern Ireland are progressing in meeting these expectations.

Table guided by considerations documented in Schunemann et al 2008