Toward a Unified Vision of Professional Counselling Identity: A preliminary Australian perspective

Ann Moir-Bussy, Ph.D., Katrina Andrews, PhD. and Trish Smith

Contact
Ann Moir-Bussy
University of Sunshine Coast
Sippy Downs, Qld.
Phone: 0400 474425
amoirbussy@usc.edu.au

Abstract

Although Australian professional counselling services are well-established, a unified vision of what defines professional counselling identity in Australia remains elusively absent. Self-regulation within the Australian counselling profession contributes greatly to the strong development of professional training, ethics, and practice principles, yet a clear understanding of what constitutes professional counselling identity remains undefined. This paper proposes that, in order to develop awareness of what comprises professional counselling identity in Australia, the views of Australian counselling professionals are necessary. This paper offers a preliminary investigation of Australian professional counsellors' views of what defines professional counselling identity.

Introduction

As a relatively new, internationally recognised field (Nassar-McMillian & Niles, 2010), professional counselling is firmly established, yet quantifying it by definition continues to be an elusive academic challenge (O'Hara, 2015; Ponton & Duba, 2009; Reiner, Dobmeier, & Hernández, 2013; Woo, Henfield, & Choi, 2004; Spurgeon, 2012). While many descriptions abound, each being contextually valid, a universal definition seems to defy unanimous agreement (Prosek & Hurt, 2014; Reiner et al., 2013; Woo et al., 2004). The absence of an over-arching international identity hinders the professions capacity to achieve clarity around the role of counsellors, professional unity, parity with other professions, and to establish a clear future (Calley & Hawley, 2008; Reiner et al., 2013; Woo et al., 2004). According to Woo et al. (2004), "The … survival of the counselling profession depends on counselling's quest for establishing a clear, common professional identity" (p. 13; Myers, Sweeney, & White, 2002; Prosek & Hurt, 2014). Similarly, Reiner et al. stated that "the likelihood of the counselling profession achieving equal recognition as a mental health discipline … [depends] on its ability to clearly articulate [its] professional identity …" (2013, p. 174).

The history of licensure within the counselling profession originates in the United States of America (U.S.A.) when, from the early 1970s onwards, licencing progressively occurred (Gladding, 2014; O'Hara & O'Hara, 2015). While Malaysia, China, and Canada legally require registration of professional counsellors, Australia and the United Kingdom are among countries where mandatory regulation through external registering bodies is not required (Australian Institute of Professional Counsellors Institute In Brief, 2012; Mulhauser, 2016; Pelling & Sullivan, 2006). However, voluntary membership with the (self-regulating) Australian Counselling Association (ACA), and the Psychotherapy and Counselling Federation of Australia (PACFA), provides Australian professional counsellors with registration (ACA, 2016a; ACA, 2016b; PACFA, 2016b).

America, Canada, South Africa, New Zealand, and Singapore have begun researching professional counselling to *establish a unified professional identity so that counselling may flourish as a profession* (Calley & Hawley, 2008; Gale & Austin, 2003; Gladding & Newsome, 2004; McLaughlin & Boettcher, 2009; Myers, Sweeney & White, 2002; Rodgers, 2012). Without it, the profession's internal fragmentation will continue to impact upon professional advancement and recognition (Rainer et al., 2013; Calley & Hawley, 2015).

Gazzola and Smith (2007) identified that inappropriate reliance on counsellors by the public and allied health professionals for treatment of mental health concerns impedes counsellor efficiency, profitability, and emotional sense of being respected. Using the Professional Identity and Engagement Scale (PIES) and the Professional Identity and Values Scale (PIVS), Prosek and Hurt (2014) found that as counsellors' sense of professional identity develops with increasing experience over time, and shifts from being more externally derived to more internally-perceived, lack of positive professional experience is detrimental to the development of professional counselling identity (Prosek & Hurt, 2014).

The 2010 American Counselling Associations (A.C.A.) "20/20: A Vision for the Future" Conference in Pittsburgh, Pennsylvania was a reaction to criticism that the counselling professions in-definity impacts upon associated professional activity (Kaplan & Gladding, 2011). The conference proposed that counselling define itself as a professional entity distinct from but working with other mental health professions (A.C.A. 2016; Kaplan & Gladding, 2011; Kaplan, Tarvydas, & Gladding, 2014). With the overarching theme being *Promoting Unity While Affirming Diversity*, its

definition that counselling is "… a professional relationship that empowers diverse individuals, families, and groups to accomplish mental health, wellness, education, and career goals" was endorsed by 29 major counselling organisations (Kaplan & Gladding, 2011, p. 366). Of seven areas identified as being in critical need of attention, "strengthening identity" most-directly relates to initial discussions regarding what constitutes professional identity (Prosek & Hurt, 2014).

Australia recently entered discussions regarding the need to define professional counselling identity. Viewing it to be comprised of an external context (professionalization through, for example, self-regulation, accredited training and practice principles, etc.), a collective context (collective professional identity - how professional counselling is perceived and how practitioners are perceived to be acting as professional counsellors), and an individual context (individual counselling identity - how counselling professionals perceive themselves within the field), the authors of this study propose that further research will assist the development of an over-arching professional identity (Alves & Gazzola, 2013). Additionally, they propose that developing professional identity based on professionalization (O'Hara & O'Hara, 2015; Pelling & Sullivan, 2006) potentially distorts the creative essence of true professional counselling identity (Alves & Gazzola, 2011; 2013). These views are empirically supported by Prosek and Hurt (2014, p. 284), who found that "… 97% of respondents defined counsellors in universal terms rather than by their identified specialty areas", and is further supported by Alves and Gazzola (2007; 2013), and Mellin et at. (2011), who reported that counsellors find their individual professional identity mainly through their personal work values, skills, and knowledge (Calley & Hawley, 2008; Ronnestad & Skovholt, 2003). Alves and Gazzola (2013) further found that counsellors viewed their professional identity was intrinsically enmeshed with their personal self.

In compliance with contemporary commercial requirements, Australian professional counselling training and practice are standardised through accreditation standards, ethical standards, and pathways for credentialing counsellors (ACA, 2016a; Psychotherapy and Counselling Federation of Australia, 2016a). These help to form national standards which contribute to professional and statutory accountability while allowing for individual authenticity in the personal counselling experience (Pelling & Sullivan, 2006). For example, the University of the Sunshine Coasts Undergraduate and Masters counselling pathways are fully accredited with the Australian

Counselling Association and the Psychotherapy and Counselling Federation of Australia (University of the Sunshine Coast (USC), 2016a), with eligibility for enrolment in supervision requiring application for and receipt of a current Blue Card (Queensland Government Blue Card Services, 2016) and in some circumstances, passing a Police Check (USC, 2016a.). Course accreditation with the Australian Counselling Association (ACA) and the Psychotherapy and Counselling Federation of Australia (PACFA) enable eligibility for membership with PACFA, ACA, and the Queensland Counsellor Association (QCA) (USC, 2016a). The ACA specifies that courses of study meeting its accreditation standards are those being primarily focused on "… Counselling, not Social Work, Welfare, Psychology etc" (ACA, 2016a.). Registration through membership with self-regulating bodies PACFA and/or ACA requires that counsellors are able to perform significant, in depth therapeutic work with clients using various therapeutic approaches using skills that have been taught and assessed beyond the realms of theory (ACA, 2016a; 2016b).

A major issue plaguing efforts to define counselling as a field in its own right is its professional proximity to psychology (Hanna & Bemak, 1997; Skovholt, Rønnestad, & Jennings, 1997). Many counselling concepts are empirically grounded in psychological theories, yet their core scopes of practice differ. While counselling assists all aspects of mental health at different levels, it utilises different frameworks and therefore different skill-sets (largely non-clinical, and non-diagnostic and without psychometric testing) to that of psychology (Ivey, D'Andrea, & Ivey, 2011; Nassar-McMillan & Niles, 2010; PACFA, 2016a). Counselling research is often precursory to further detailed scientific investigation (McLeod, 2011), being generally qualitative and typically non-statistical or less-statistical than psychological research, which relies upon quantitative, statistical outcomes in order to increase research validity (Australian Psychological Association (APA), 2016).

While the contextually shared use of the terms 'counselling' and 'psychotherapy' contributes to confusion within the mental health industry and among the public (O'Hara & O'Hara, 2015), this papers authors suggest that the detail in the work styles varies between the two fields to the extent that the terms need not be a misguiding source of confusion, any more than other fields with shared theoretical bases. While over-lapping skills between counselling and psychology professions perceivably diminishes counselling's credibility and stature (O'Hara, 2015), this study's authors

suggest that theoretical connections do not realistically over-write one profession by the other any more than sub-sectors of other healthcare areas such as those between paramedics, nursing, and medicine. Additionally, over-lapping skill-bases may be more-a-result of professional transience transferring skills across from one professional area to another during times of job change (e.g. from counselling to psychology, and vice-versa). In terms of criteria requisites for recognition as a field in its own right, counselling meets most, but lacking a definitive identity is detrimental to this achievement (Hanna & Bemak, 1997).

This exploratory Australian study aims to investigate counselling practitioners' perception of individual professional counselling identity, with a view that as experience develops and deepens personal identity, counsellors increasingly *grow into* their role and contribute to collective and external counselling identity. It is hoped that the findings are able to contribute to further Australian research that will assist in the development of an international professional counselling identity.

Research aims

This study aimed to:

- Explore Australian counsellors' perspectives of their professional counselling identity (how practitioners identify within themselves as practicing professional counsellors, including how this self-perception increases with experience).
- explore Australian counsellors' perspective of the industry's collective professional identity (how professional counselling is perceived externally, how practitioners are perceived to be acting as professional counsellors, and how counselling is positioned in the health field and in relation to professions which appear to offer similar services, such as social work and psychology).

Method

Research Design

A combination of brain-storming within focus groups, and approximately 20 on-paper survey questions was used. The focus group participants completed both tasks.

Participants

Participants (*N*=30) were professional Counsellors attending the 2014 Australian Counselling Conference. The rest of the participants were counsellors who completed the online survey but were unable to attend the focus groups.

Procedure

At the conference, a short presentation was given on the concept of professional development, informing participants of what had been completed in other countries. Participants were then grouped into six (6) focus groups comprised of approximately five (5) participants each. Participants discussed what they saw as the components that together contributed to a sense of professional counselling identity. Answers were written onto large sheets of paper, using texta pens. In addition to their collated response another 20 participants received a paper-based survey (Appendix A), with the same questions posed to those at the Conference and they emailed their responses to this study's main author, Dr. Ann Moir-Bussy, for compilation.

The survey questions were designed to draw out the respondents' perceptions of:

- core values, characteristics and influences contributing to sense of a professional counsellor identity
- development of professional identity in practice over time
- what is needed for the counselling profession to achieve national professional recognition, and
- how to describe the counselling profession and how it relates to social work and psychology.

Results

Individual/Internalised Identity

Respondents spoke of a congruence between their sense of self and their identification as a professional counsellor. Personal characteristics listed as congruent with being a counsellor were:

- genuineness, honesty, authenticity, transparency, sincerity
- compassion, a caring nature, kindness, warmth
- curiosity, openness, humility, non-judgemental regard
- attentiveness, patience, a good listener
- empathy, understanding, encouraging, supportive

- confidence, resilience, courage
- respect, clear boundaries, self-awareness, integrity
- personal maturity, self-reflective practice
- sense of humour

> *I feel that my core values and characteristic is my rapport that I have with people, good communication, empathy to understand how people are feeling or understand, their emotions in different situations. I feel that my witty sense humour supports break the ice in different situations.*

> *Ability to respect and adhere to boundaries, confidentiality and unconditional positive regard towards individuals. Also ensure the integrity of professional relationships.*

Respondents described their interactions with clients as being characterised by "*a genuine positive regard for all people*", "*listening with openness*" and experiencing a sense of "*gratitude, sacredness*".

Several spoke of experiencing their occupation as a counsellor as a calling:

> *I feel a sense of being home, home within myself and in the profession that I have chosen. The dictionary defines home as a) a place of origin and b) a goal or destination. Both are relevant in this case, as I searched for meaning, identity and self.*

Self-reflection is a task for the client and a core activity for the professional counsellor, and so having self-reflective tendencies was seen as a strength.

> *I am naturally reflective, this is another way of how I learn and grow. I continuously evaluate what I have done well and what I can do better next time. If something doesn't work, I like to think about it and ask myself why and then actively seek ways of improvement. I accept when I am not sure of something and have the courage to seek help from supervisors, colleagues, research etc.*

This imperative toward personal improvement sits naturally with placing a high priority on ongoing professional development and the delivery of professional services, indeed, with identification of self as "professional".

> *As a professional counsellor, to the Counselling profession as a whole and to my past, present and future clients, I continually work towards offering the best service and support that I am able. Without this, there is no service, no support, and possibly no hope. I do not want this, therefore I constantly strive to be the best I can in this domain – this influences my thoughts, attitudes and behaviour. 'Counselling' or 'the Counsellor' is who I am, it's who I want to be, I don't believe there can be any bigger influence.*

> *I am committed to partaking in activities for my own continuous professional and personal development, developing good practice and moral qualities as a therapeutic practitioner including, empathy, sincerity, integrity, resilience, respect, humility, competence, fairness, wisdom and courage.*

> *I work very hard to offer a safe, empathic, professional and ethical service.*

> *I believe as human beings we never reach a point at which we can say we know everything and so I never stop learning. I have a hunger for growth and knowledge… I actively seek new and various learning experiences via any means I can, e.g. workshops, supervision, webinars, DVDs, reading, peer support - counselling and psychology colleagues, networking events, volunteering etc.*

Other spoke of self-identification as "professional"

> *My professional identity is influenced by a belief in the value of the work I do.*

> *I pride myself on my professionalism. Before training as a counsellor I saw different counsellors for my own therapy. I learnt early on what I liked in a counsellor and I replicated this in my own business. I treat people how I want to be treated.*

> *Constant professionalism in every aspect of my business. From first contact be it email, text or phone call a constant professional reply. This includes a logo, letterhead, and caring empathy when people call. Booking system and pricing is consistent, prompt and efficient.*

Consistent professionalism in my appearance, neat, tidy dress sense. Environment is private, clean, tidy and professional in furniture and layout.

Ethical approach to life as well as my personal and professional interactions and endeavours.

Respect: I have worked hard to gain the respect of my clients and fellow professionals. I am also respectful of my client's rights, giving them dignity and acceptance of varying cultures, age, gender, religion and life experiences without prejudice.

The influence of counselling theories themselves in identifying one's ability to change and how these might be shared with clients…

The concept of neural plasticity.

All of the counselling theories have influenced me in one way or another:

- *Psychodynamic theories remind me that there are dynamics which have not yet surfaced from my unconscious, so it is imperative to foster self-awareness and an openness to explore my motivations in what I think, feel and do; to ensure effectiveness and ethics, both personally and professionally.*

- *Phenomenological theories remind me of my free will and drive to self-actualize. Counsellor characteristics and attitudes in these theories lay the foundation for my professional identity (unconditional positive regard, genuineness, empathy, openness etc.).*

- *Behavioural theories remind me of how my behaviour may have been shaped*

- *Cognitive-Behavioural theories are significant to me and highlight that I am a choice-making being and that I can redirect my direction and consequences by changing my thoughts and actions. These CBT/RT theories are pivotal in my life as well (personally and professionally).*

The respondents unanimously acknowledged the growth of their personal identification as a professional counsellor over time, generally attributable to:

- interacting with their peers and supervisors – undertaking professional development activities such from getting feedback and advice from supervisors and mentors, from ongoing professional training and networking, and sharing and developing understandings with peers
- in practice with their clients – from their experience counselling clients, and from participation in workplaces and interacting with practitioners in related fields
- connecting with themselves – as an outcome of personal reflective practice.

Almost all respondents noted ongoing professional development – attending workshop and further training, undertaking supervision and gaining feedback – as significant in their developing sense of professional identity. The sense of being supported feeds a hunger for extending their understanding.

> *I take a great deal of wisdom from those who have been in the industry for many years and learn from these professionals in any way that I can.*

> *... professional development and supervision ... have both increased my self-belief and confidence in my abilities.*

Supervision provides more than imparted wisdom; supervision is also seeing as providing a safe and supportive space which allows for openness and for gaining validation for shared experience. Through this grows a sense of connection to a community of ongoing learners.

> *Having supervision that challenges and supports me, and being able to say "I don't know what I'm doing here". With the passage of time and having an accountability partner, I have grown in my confidence in utilizing my life experiences in sharing psycho-education about life transitions.*

> *Recognising that there is no magic that other counsellors have, that I somehow missed out on – we are all on the way.*

The sense of being professionally accountable within the counselling community builds a stronger sense of professional effectiveness, as do interactions with professionals in related fields:

> *Professional interactions with other professionals, whether they are psychologists, counsellors/psychotherapists, mental health nurses, psychiatrists or social workers; this*

> *leads to insights into other approaches, discussions regarding professional development, and the feeling that my professional opinions are valued.*

In practice as a professional counsellor and in relationship with clients, their sense of themselves in the role of counsellor develops, "*... in depth and breadth, moving from principles and concepts into live embodied dimensions*". Respondents spoke of growing in their ability to encounter the client in their own space; of developing observation skills that better enable them to hear and support the client's own path; of learning to trust the process and the client's capacity to find their way forward. There is a growing maturity in embracing the practicalities of their own role in the interaction, of gaining a more realistic and practical sense of personal agency regarding the possibilities and constraints on their ability to help clients make changes, of engaging more deeply in self- and other-care through setting boundaries, of understanding the implications of duty of care. And also of a developing sense of their own presence in the process, of their role as "*the happy person in the room*", of "healthy" and "unhealthy" somatic transferences.

> *I think one of the major changes is that I now see a counsellor as one who is a good listener. I find myself listening more to clients these days and speaking less. Earlier on I believe I spoke more and listened less. I believe that I realized along the way that if you don't listen and have a sense of what are person really needs you may be unhelpful, taking them in a direction that is not appropriate or helpful.*

> *Truly understanding the use of self within the therapeutic space and across professional boundaries and accept the responsibility of this positioning.*

> *It is impossible to separate the person from the counsellor - it's the same package (which is good and bad but it is the way it is I guess). I am much more confident in the role now than when I started at the age of 18. I'm glad I started off with such wonderful dreams regarding my ability and view of the world. Life experiences, counselling experiences, heartbreak, knowledge, time - life in general, I am a different person to the little novice who wanted to change the world.*

> *That I have the tertiary skills, ability and knowledge to work with at risk people so they do not get lost has given me confidence and strength to put myself in situations and work environments where I can reach the most exposed people*

This vision extends into the future as well as into the past, as respondents spoke of a sense of journey, of seeing themselves as participating in a "*never-ending learning experience*", of being flexible and open to change in that "*there is something new to learn every day*", of having a willingness to "*disregard old values that no longer serve*".

> *I see my professional identity as a journey. I have moved through different phases and yet there are still experiences and interactions that will inevitably change my current sense of identity.*

> *Change needs to occur progressing from novice to advanced counsellor otherwise knowledge and practice becomes arrogant, unbalanced and ill informed. I have always focused on making professional supervision and professional development a key part of my professional practice to ensure that I have not become narrow and biased in my thinking and behaviour.*

Collective Identity

The respondents in this study revealed a shared understanding of the relationship between the concept of collective identity, the core philosophy of counselling, and the methodological approach of counselling – how the counsellor perceives and engages with the client. Respondents unanimously reported the view that the counselling service/practice is client- centred and client-directed, individualized, strengths-based, empowering for the individual, supporting client self-determination, and coming from the understanding that: Through support and guidance most people can resolve the issues that they are facing.

> *I work holistically and uphold my client's autonomy to be self-directing.*

The philosophy of "do no harm" reportedly guides counsellors to approach clients with respect, dignity and fairness.

> *The value that I think contributes most significantly to my professional identity is 'do no harm'. If I keep this in mind, I will always have the best interests of the client in mind.*

> *It informs a professional approach that gives due consideration to working with clear boundaries, a strong ethical grounding and ethical practice frameworks, confidentiality, accountability, and respect for client autonomy.*

Professional counselling acknowledges and embraces diversity of cultural and personal experience where-in clients are viewed without judgement or bias, as individuals. The counselling profession draws on a diversity of modalities and approaches to meet each individual in their own space:

> *Respecting and being accepting of personal experiences and diversity (cultural, gender and economic to name a few) and being non-judgemental of individuals.*

> *Delivering services that are tailored to an individual and their needs, while maintaining a flexible and holistic approach.*

> *Having the freedom to not have to impose particular treatment models on a client.*

> *Having the freedom to have non-directed conversations.*

> *Counselling is not a sub-set of skills.*

The relationship with the client is seen as being based on compassion, acceptance, respect, rapport, empathy, active/effective listening, non-judgmental and non-labelling, clear boundaries, confidentiality, and providing a safe environment for the client.

> *Treating all individuals with respect, dignity and equality (and fairness).*

> *Unconditional positive regard for clients: They do not have to earn my respect, they have this, irrespective of anything they think, say or do.*

> *Everyone is important. Everyone deserves to feel loved and respected.*

More than this, it is about providing a sense of safety for the client:

> *A major part of this concept is being able to take judgment out of any situation.*

> *By allowing each client to speak openly and honestly in a session will help them to feel safe. As a professional, I believe it is my duty to ensure that I provide a safe environment both physically and emotionally for all clients.*

Counsellors acknowledge being an active component in the client relationship and experience:

Being honest with myself and clients about my strengths and my limitations in my counselling practices

Membership

Many respondents viewed their membership with a representative professional organisation as indicative of their commitment to professionalism and of a certain level of professional conduct, as evidenced by:

- self-identification as a member of a professional community with agreed standards and a shared philosophy of practice

- ongoing commitment to professional development via further training and supervision/mentoring

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- ongoing commitment to professional development via further training and supervision/mentoring

- commitment continuous improvement through self-reflective practice

- recognition of a certain level of training/study

- ethical practice as evidenced by acknowledgement of a code of ethics

- engagement with an organisation that advocates on behalf of its members to advance the profession in the eyes of the general community, the profession itself, other health professions, and government regulatory bodies.

- access to learning resources, training, professional networking and mentoring/supervision.

- holding Professional Indemnity Insurance covering malpractice as well as

  professional, public and products liability.

- holding a current blue-card for working with children, young people and

vulnerable adults.

Being a member of ACA gives me recognition for my qualification … professional development opportunities and work experiences. I am required to have a certain number of hours of professional development, as well as certain number of hours of supervision from an accredited supervisor. I have access to various learning resources and an opportunity to learn from workshops, seminars, latest research etc. In supervision I learn from the experience of others who have been there before me. Supervision also gives me another pair of eyes to double check if there is something I can do better or whether I need to see things from an angle I might not have considered or whether I am already doing well and on the right track.

Membership of a representative professional organisation also brings a sense of identifying with group of practitioners who have shared goals and ethics, a group that acts to establish a publically recognisable reputation and credibility for the counselling profession.

Belonging – being a member of ACA means I belong to a group of people who are in the caring profession and have similar goals to me – to contribute to the wellness of others.

Externally-Related Identity

Counsellors, social workers and psychologists are seen as having a similar overall goal, which is to improve the quality of life and enhance the wellbeing of individuals, families, couples, groups and communities. Counselling is perceived both in terms of its own strengths, and also in terms of how it articulates with these other two helping professions.

Counselling is generally defined in terms of:

- focusing on wellness and a return to wellness, on mental and emotional wellbeing
- being grounded in acknowledgement of client autonomy; viewing the client's goals as paramount
- being non-diagnostic (and non-labelling); non-judgemental, accepting of the wholeness of the client

- supporting the client toward long term sustained change (rather than short-term intervention) with the goal of empowering the client
- drawing on a diversity of therapeutic approaches, a range of modalities.

Survey respondents expressed this as:

… seeking to place the person in their wholeness at the centre of the process

… working with people to enable them to identify their own solution and identify strategies to resolve or come to a point of acceptance of their situation

… working with client/s in the here and now, engaging in a way which empowers the client/s to address their issues.

… assisting clients in exploring options to [experience] healthier lives and relationships.

… a therapy designed to listen with no judgement in a safe environment… giving the client the ability to recognise their problems and the skills to make the necessary changes for an improved quality of life.

… a heart-centred approach to listening that offers practical assistance with change – similar to that of psychology without the labelling.

The counsellor views the client as the expert in the room. The counsellor's role is to listen carefully, to provide a space in which the client can see their path forward. As such, counsellors "*are not problem solvers*". The counsellor's role is collaborative, the intention being to build a "*therapeutic alliance*" with the client. The quality of the working relationship is important in setting the atmosphere for the client to own their understandings, conclusions and path forward.

I believe Counsellors focus on client's concerns and difficulties and [this] includes understanding people's patterns of thoughts, behaviours [and] feelings and the ways in which these may be problematic in their lives. Studying counselling involves learning how to assist people to develop understanding about themselves and to make changes in their lives.

Just as we are seeking to define the professional identity of counsellors free of misconceptions, it must be noted that social work and psychology are also subject to misperceptions. Such misperceptions may well be present in some of the following responses.

Practitioners in all three fields are seen to:

> *...use similar counselling theories, therapies and techniques to help clients clarify and explore issues they may be struggling with, [to] develop strategies and increase self-awareness.*

Counselling is seen as focusing primarily on prevention, whereas social work and psychology are seen as being more oriented toward intervention. Clients seeking assistance in the early stages of distress or concern can avoid problems escalating to the point where the services of psychologists and/or social workers are needed to address more serious mental health, welfare or safety issues. A recovery framework informs counselling, a perspective that all people can become well, "*whatever well means to them*".

Additionally, counselling is seen as being less constrained by a particular framework for practice, enabling counsellors to draw on a range of modalities in meeting the client in their particular space.

> *I view [Social Workers and Psychologists] as being somewhat 'bound' within the system to a much larger degree than Counsellors. They have an agenda or 'a box to tick' and must fulfil this criteria as part of their role. Counsellors do not have this nor do they function at this level. [Counsellors] focus holistically on the person/people in front of them.*

While the discipline of Social Work promotes social development and change, human rights and the empowerment and liberation of people, social workers are generally seen as being tasked with the practical aspects of "*connecting people to services, networks*", engaging with clients with the purpose of maximising their interactions within the complex of social systems. A key point of connection and cooperation between counsellors and social workers lies in referring clients in need of social support to social workers.

> *Social workers provide a greater degree of hands-on case-work than counsellors or psychologists, for instance sourcing services that provide food packages or accommodation for people in need. Counsellors and psychologists tend to provide referrals to services with social work support that can help the client with receiving the services that meet their physical needs (e.g. food, accommodation, financial aid).*

Whereas social workers focus on connecting clients with a supportive system, psychology and counselling share a focus on the individual. Of course, many social workers incorporate counselling training into their practice.

Psychology is seen as being more of a scientific and analytical discipline than counselling, with the psychology approach being clinical and process-oriented. Psychology trains practitioners to view clients via a pathology perspective, whereas counselling takes a holistic view of the client.

> *Psychology is a science interested in understanding human nature, behaviour and the brain. Psychologists vary in their focus of study such as research, neuro-psychology, clinical, experimental, sports, psycho-educational assessment, and so on.*

> *Psychologists tend to use more written assessments of client self-reports, whereas counsellors listen to the words and images clients use to enable them to be more solution-focussed.*

> *… counselling professionals do not scientifically study behaviour and its causes.*

> *Rather, the counsellor may implement strategies to assist in addressing problematic behaviours.*

> *Psychologists study human behaviour and emotion, with practical and research skills that can be applied to a wide variety of fields that include health, education and management.*

Psychology training does not necessarily specifically encompass counselling skills, even though the intent is still to help people have more functional experiences in life.

> *Psychologists train to be psychologists. The skills of counselling may or may not have been a focus in the psychologist's training.*

Counsellors work with both clinical and sub-clinical populations, but unlike psychologists, counsellors do not diagnose – or label. Counsellors have the option of referring a client on to a psychologist or other medical professionals for diagnosis where this appears to offer benefits for their situation.

> *Clinical psychologists help with the diagnosis (something a Counsellor does not do) and treatment of mental illnesses across the lifespan. Most psychologists also help mentally healthy people to find ways of functioning better.*

Discussion - Where to from here?

Individual Professional Counselling Identity

This study's results indicate that factors associated with individual identity and collective identity feature strongly in Australian professional counsellors' perception of what constitutes professional counselling identity, with factors associated with individual identity being most strongly associated. This is supported by Canadian findings that individual identity is perceivably stronger than collective identity (Alves & Gazzola, 2013). While factors associated with professionalization also appear to be important, this study did not identify them as integral to professional counselling identity per se.

A direct relationship between participants personal 'self' and their individual professional identity exists, being inter-related, inseparable, and apparently the prime focus of professional counselling identity. The professional self reportedly results from integration between personal self, training, practical experience, and development of knowledge, over time. Professional counselling is a united journey of both self-growth and professional growth.

This study identified congruence between the sense of self and individual professional counselling identity to be greatly important to individual counselling identity. The capacity for expressing personal self comfortably into and as part of the work domain was directly related to participant's personal need to be genuinely interested, caring, empathic, respectful, and non-judgemental towards clients. If perceived individual counselling identity is a process that develops from being externally derived during professional infancy to being increasingly internally derived over time as experience broadens and deepens professional ability and congruence, then this finding is supported in those of Prosek & Hurt (2014), who identified that personal counselling identity deepens with experience over time.

Identifying as a professional is very important across all participants, with ongoing personal development/improvement, self-reflecting, and membership/registration being integral.

Collective Identity

Collective identity involved being perceived as fair, honest, and focused on developing self-directed client autonomy, and is reportedly significant towards strong professional counselling identity development.

Participants viewed the client relationship as based on compassion, and respect, and being non-judgemental, non-labelling, multi-culturally aware, and safe for the client. Outcomes of brainstorming discussions relating to collective identity resembled those for individual identity, indicating that how the counselling professional views the profession is reflected in the way they present their services to clients, so inevitably it is anticipated that the client's perception of the profession is congruent with the professions views of its collective identity.

External Identity

This study found that while professionalization was associated with the greater definition of professional counselling, it was not considered an integral ingredient of professional counselling identity. Instead, professional counsellors' individual professional identity and collective factors were main contributors to their sense of professional counselling identity.

While issues related to professionalization are connected with matters regarding external registration, voluntary membership-based registration with PACFA and/or the ACA were considered to represent participants' commitment to their professional capability and conduct. In this context, membership/registration is an expression of individual and collective professional counselling identity.

In order to move forward with the information gathered in this study and identify how it can assist the Australian counselling profession to advance, a range of proposals have been developed:

- Define the *counselling professional identity* more closely within the counselling community using increased surveying and discussion of practitioners', educators, and students, and also identifying an end-point at which the goal may be considered 'reached'. It is important to recognise at what point 'we're done' – what's the aiming-point, what's the end-point, how will conclusions be drawn, decisions made, and position established?

- Building credibility for the profession and increasingly developing effectiveness in counselling through further supportive evidence-based, quantitative and qualitative research. This will provide substance to the image of Counselling as a profession. More research needs to be conducted on areas such as "do clients return?" and "What outcomes do clients experience?" This will also assist the profession internally, enabling the focus to transcend self-justification to become a focus on the strengths of counselling.

- National accreditation, and professional level expression of job title, via:
    i) having the membership of a peak representative body;
    ii) a minimum tertiary education and training level requirement;
    iii) firm commitment to a standard code of ethics;
    iv) meeting requirements for ongoing professional development/training;
    v) meeting requirements for ongoing supervision

- Enhancing the positioning of the profession via:
    i) Advocacy with government bodies/agencies by the peak representative body/ies;
    ii) Formulating and establishing a position in the team approach within the health profession;
    (iii) Gaining mental health care plan access;
    (iv) Marketing professional counselling as a profession in its own right – raising its profile through educational marketing which would serve to position counselling as a profession in its own right, in the minds of the community, health professionals, government and regulatory agencies, and within the broader counselling profession.

As long as anyone can open a counselling practice without a recognised level of certification, the profession will continue to be subject to distrust.

Counselling is such a blurred word – 'everyone is a counsellor'. Funding bodies are not definitive as to what 'counselling' is as part of service delivery and what qualifications are required. National recognition requires clarification of what counselling is and what qualifications are required to claim the position of 'counsellor'. Although not the best definers, these are the standards that the health and general community use as a yardstick to consistency of service and practice. This may require registration with a respected national body.

The mentality and the stigma around counselling needs to shift, and a lot of money

is needed in advertising to begin making this happen so that counselling is similar to having a personal trainer. It's not something to shy away from.

- Compulsory registration with a peak national body that is proactive and lobbying on behalf of the profession, raising its profile, establishing a professional public image (and contributing to social policy) would send a clear message that a Counsellor has achieved a substantial level of initial and ongoing training, and that the Counsellor has committed to adhere to a publicised Code of Conduct. This would put counselling on par with other professions (e.g. social workers, teachers, psychologists, nurses) and gain it due credibility and raise its profile.

- Clarifying and defining just what it means to be a Counsellor – role and function of a Counsellor, the skill set, the outcome objectives, the underlying philosophical structure – will help with positioning the profession both in the minds of the general community as well as in relation to other health professionals, enabling a team approach to client care.

  … We need Government on board to begin seeing counselling as a preventive for mental health issues and something that is very important

- Establishing both an overarching standard as well as recognition of the diversity of specialisations and approaches taken within the field.

- Media campaigns and other educational approaches will develop a public image of professional Counsellors as having recognised qualifications and an ongoing commitment to professional development, assist in building acceptance, and positioning Counselling in relation to other healing professions.

  I think that people need to be aware of the difference between mental health professionals. Each group of professionals have their own unique strengths and can offer different things to different people.

- This knowledge conveys

  An appreciation of the multidisciplinary skills set possessed by some counsellors now that we are edging away from the medical model and moving towards a more holistic, recovery oriented approach to the quality of life and enhancement of the wellbeing of individuals.

The perceptions given by Australian counselling professionals identified that individual and collective professional identity feature more strongly towards professional identity. However, Australia's soundly established criteria for the attainment and maintenance of professional standards and registration/regulation factored as important in the maintenance of a strong sense of professional identity.

The findings of this study present a baseline of information upon which a larger, more representative survey of Australian professional counsellors (registered with Australia's peak professional counselling bodies) is able to be developed.

With this in mind, the intention of future studies should be to build on this study and address identified gaps relating to other papers, following this structure:

i) **Collective identity**

- Level of training expected (absent from this study)

- Ongoing professional development/workshops

- Supervision

- Membership of representative body / code of ethics

- Agreement on counselling

ii) **Personal identity**

- Alignment of personal characteristics with the character of a professional counsellor

- Professional behaviour

In the American and Canadian contexts, there appears to be a delineation of counsellors from other mental health professionals, by defining themselves as practitioners with a "developmental, prevention, and wellness orientation toward helping". This may indicate that

- there is a lack of unity within the profession, and

- the unique professional identity of counsellors remains over-diversified.

Limitations

This study was limited by the small number of participants surveyed. Intended as an initial, explorative research project, it is anticipated that larger studies will follow.

Conclusion

This study was borne out of awareness that, despite the "20/20 Vision for the Future of Counselling Profession" conference principle that a shared, common professional identity is critical for counsellors, the international counselling profession is no-closer to achieving this aim. The over-arching aim of this study was to contribute to the quest to identify an international professional counselling identity by contributing a starting-point for an Australian perspective of professional counselling. It is anticipated that the limited pool of Australian research on this topic will increase to further develop knowledge of what defines the field of professional counselling.

Three major areas (individual- and collective- professional counselling identity, and external factors) appear to embody the over-arching concept of what constitutes professional counselling. This study's research suggests that professional counselling identity is more directly derived from individual and collective factors, while external identification appear to be more associated with

professionalization which, in the view of this study's authors, is a sub-category of both individual and collective counselling identity, and whose infrastructure is associated with administrative/social worker considerations. These findings suggest that in developing an Australian and indeed an international definition of professional counselling identity, individual attention to the three key areas may contribute to an overall sense of belonging to a stable profession.

Further research regarding Australian professional counselling identity is necessary, and may benefit from being assisted by Australian registered professional counselling bodies. This would be in line with similar self-investigations undertaken by other nations. Developing government initiatives supporting improved professional counselling service provision to the Australian community will benefit the greater development of an Australian professional counselling identity, and will also assist in the development of the international definition of professional counselling.

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Someone I love has Alzheimer's:

The impact of caring for a 'Special Someone' who has a diagnosis of Alzheimer's disease:

A review of the literature

Judith Boyland, PhD. Candidate
Peter Innes, PhD.
Ann Moir-Bussy, PhD.
University of Sunshine Coast

Contact:
Judith Boyland
University of Sunshine Coast
Sippy Downs, Qld. 4556
Australia
Phone: 0413358234
Email: judyboyland1@bigpond.com

Abstract

This paper discusses a review of literature related to caring for a loved one who has a diagnosis of Alzheimer's disease. The review is focused through a conceptual framework that encompasses 13 key constructs: Living with dementia: transitioning; Transitioning to the role of caregiver; Transitional change; Aspects of impact: stress response; Aspects of impact: loss and grieving; The ripple effect; Support; Barriers to support; Coping strategies; Coping with abusive behaviour; Maintaining dignity in the midst of chaos; When it is time; and End of life.

Beginning with a glimpse into how life unfolds for the care receiver, the discussion focuses on the impact of lived experience and culminates with the promise from the medical world to patients and families, that they will not be abandoned.

Introduction

Initially identified as 'an unusual disease of the cerebral cortex', it was in 1906 that Dr Alois Alzheimer presented a conference paper addressing both the symptoms experienced by a patient across the last five years of her life and the autopsy findings in relation to the condition of the patient's brain following her death (Alzheimer's Disease International, n.d.). George, Whitehouse and Ballenger (2011) advise that it is now over 100 years since the condition that was to become known by the name of its 'discoverer' was formally established as a distinct disease and described in an influential German psychiatry textbook – Kraepelin, Emil. (1910). *Psychiatrie* (eighth edition). George et al. also explain that since that time, the condition (as initially described) has undergone various permutations. They further state that ongoing evolution carries important implications for the clinical treatment and cultural placement of persons who are given the

diagnosis. For, while researchers in the field of neuroscience have made huge strides in understanding Alzheimer's disease, it is still both irreversible and progressive: culminating in severe dementia and death. Perhaps the most comprehensive definition of Alzheimer's disease is presented by Summers (2014) who, referring to the Alzheimer's Association (2009) states that…

> Alzheimer's disease is a progressive disease, commencing with mild and relatively circumscribed deficits that gradually worsen to become a severe dementia with widespread and marked impairments to cognitive, social and behavioural functioning. The speed of progression of impairment is variable from individual to individual, with death occurring between two and 20 years post-onset, on average within 10 years. (p. 250).

Because of the nature of Alzheimer's disease and dementia, individuals living with these conditions can spend five times as long in hospital visits than all other causes of hospitalisation. While patients who have transitioned to an Alzheimer's related dementia are more likely to live in institutionalised health settings, the proportion of those in residential settings has increased from 26% in 2003 to 38% in 2009 (ABS 4102.0, 2012), indicating a significant rise in the focus of family and assisted caregiving. This review of literature sets the scene for a qualitative research project titled "Someone I love has Alzheimer's: The impact of caring for a loved one who has a diagnosis of Alzheimer's disease". The research investigation seeks to gain insight and understanding about the nature of the truths embodied in a world of the lived experience of informal caregivers. It is about the relationship between the caregiver and the experience of caregiving. However, while the focus of this project is on the caregiver, it needs to be acknowledged that the 'Special Someone' who is the care receiver is also transitioning from a life that was, through a life that is, to a life destined to be shrouded in a cloud of unknowing. Assuming a starting point of 'normal', (referenced as Stage One of 'Reisberg's Global Deterioration Scale' [Reisberg, Ferris, de Leon, and Crook, 2007/1982]), the intention of this review is to present a collective profile of the impact of the onset to post-death journey of caring for a loved one who has Alzheimer's. This review revisits and reframes Murray's (2016; 2005) notions of a 'world that was' and a 'world that is' to 'life that was' and 'life that is' in exploring the numerically-increasing rise of incidence of Alzheimer's disease

but relatively unknown impact of caregivers' experiences when caring for a loved one across the trajectory of caregiving

Literature Review

1. Living with dementia: transitioning

When reading reports that deal with aspects of living with Alzheimer's disease and Alzheimer's related dementias, similarities are noted across different cultural contexts. Significance of family observations of behavioural changes was noted by Williams, Klein, Little and Haban (1986) who stated that the observations made by family members of cognitive impairment and decline in a loved one, serve an important role in the description of dementia-related illnesses, such as Alzheimer's disease. Thirty years ago, Williams et al. explained that a common clinical practice was to interview family and to informally gather information about the severity and the history of intellectual impairment, such as memory disorder and loss of language and speech ability due to damage to the central nervous system. They reported the results of their study as revealing that family members made reliable judgments of everyday cognitive impairment and that observer ratings significantly enhanced diagnostic efforts: especially when used in conjunction with neuropsychological tests and also in cases in which the person with dementia could not participate in a full neuropsychological evaluation.

More recent reports also reflect the significance of family observations, with Bunn, Goodman, Sworn, Rait, Brayne, Robinson, McNeilly and Iliffe (2012) having observed that family members often recognise that something is wrong, even before the patient with dementia does. An example of the significance of family observation was presented in the work of Gierck (2015), who in discussion with her family doctor, made reference to her observations of her mother …

> I think Mum has lost a little edge too, in a good way. She's not so independent, so stoic
> that she has to battle on and do everything herself. She's allowing herself to depend on
> others. She's softening a little and it becomes her. (p. 16).

Aminzadeh, Molnar, Dalziel and Ayotte (2012) suggested that despite variations in systems of care, there seemed to be substantial consistency in core recommendations of most Western contemporary

clinical practice guidelines. These, they explained, indicated that primary care of persons with Alzheimer's should begin with "a recognition of the signs and symptoms of dementia, followed by a thorough multidimensional evaluation, sensitive diagnosis disclosure, collaborative care planning and ongoing monitoring and management of evolving needs of caregivers" (p. 86). Accurate and early diagnosis support a range of benefits, the most important being deemed by Summers (2015) to be the right of the individual to know what is happening to them, in keeping with overriding ethical codes that would not support withholding a diagnosis unless provision of that diagnosis would put the person at risk (for example, suicide) or if the person lacked capacity (M. Summers, personal communication, July 1, 2015).

Gil, Arroyo-Anllo, Ingrand, Gil, Neau, Ornon and Bonnaud (2001) directed research towards the correlation between onset of dementia and the impact on a reflexive sense of self-consciousness. Here, impact was presented as being the object of the person's own awareness and in this situation, focussed on the sensitivity of transition from what might be deemed to be 'normal', to the progressive onset of dementia.

In a study focused through the responses of participants in urban Iran, Mazaheri, Eriksson, Heikkilä, Nasrabadi, Ekman and Sunvisson (2013) consulted with six women and nine men who also made reference to the impact on family members. All participants were able to give concrete examples of their experiences of living with the progressive debilitation associated with Alzheimer's and reported the emergence of five common themes as they reflected on the transition from what Murray (2005) might describe as 'the life that was' to 'the life that is' . . .

1) struggling with a changing life which included participants' feelings about how they were perceived in the eyes of others

2) the irritation of forgetfulness and the increasing inability to undertake simple tasks

3) increasing dependence on others and being a burden on loved ones

4) feelings of embarrassment, incompetence, shame, confusion and loneliness

5) longing to be valued and finding strategies to deal with and mask progressive debilitation, even prior to diagnosis.

Cognitive and functional degeneration were said to be challenging to the participants' understanding of themselves as competent people and they spoke of feeling deeply unfulfilled, with

the reactions of others making them feel as if they were no longer themselves: but some other person.

Similar thoughts were expressed by participants in a study undertaken in the United Kingdom by Benbow and Kingston (2014), who suggested that producing a narrative that described the feelings of care receivers as they transitioned through Alzheimer's disease was both valuable and engaging and had the potential to contribute to future advancements in dementia care.

2. Transitioning to the role of caregiver

Recognizing and acknowledging that a 'Special Someone' who is deeply loved has Alzheimer's disease can be a distressing and emotional time. And while preparing for a diagnosis, support is needed by both caregiver and care receiver. However, all too often, this support is lacking. Emotions can run high and as reported by Varela, Varona, Anderson and Sansoni (2011), can range from shock to anger to grief and in many instances, there can also be associated stress, anxiety and depression. According to Varela et al., the first step in transitioning to the role of caregiver is to recognise the stage symptomatology being demonstrated in that 'Someone Special' and to seek formal diagnosis: as the decline in ability to function is co-related with the progression of debilitation. It is also reported by Varela et al. that significant aspects to be considered in taking on the role of caregiver is to determine who is to be in control of decision making, how needs are to be met and where that 'Special Someone' is to live after diagnosis.

In a study of spouse and adult child caregivers, Ott, Sanders and Kelber (2007) reported on the co-existence of grief and personal growth while transitioning to the role of caregiver. They explained that while grief was deemed to increase as the severity of the disease increased, the majority of caregivers who participated in their study also reported experiencing personal growth. Black, Gauthier, Dalziel, Keren, Correla, Hew and Binder (2010) focussed investigation on 'baby-boomers' and the burden of care. They reported that participants identified several areas of burden of care, including negative effects on emotional health: demonstrated through increased incidence of depression, more stress and greater fatigue. Financial costs were also deemed to be a significant factor in magnifying the burden of care.

Minority related aspects deemed to influence stories of caregiver transitions, included ethnic identity and associated cultural resources. In a multicultural study undertaken by Hinton and Levkoff (1999), the authors noted that African-American, Irish-American and Chinese-American caregivers focused their stories through a "what is at stake" lens (p. 468): seeing Alzheimer's as a disease that erodes the core identity of a loved one, deteriorates their minds and results in a loss of identity. Hinton and Levkoff also noted that for Chinese caregivers, the focus on transition emphasised how families might manage confusion and disability: changes ultimately construed as an anticipated and expected aspect of growing old. Further outcomes of the Hinton and Levkoff study revealed that Puerto Rican and Dominican families perceived their elder's illness in a context of tragic loss, separation, loneliness and family responsibility and their transition was deemed to have a loss and grief focus.

Calasanti and Bowen (2006) and Russell (2007) also referenced the role of the male as caregiver: spouse, partner, son. Focussing on the way gender might influence caregiving, it was suggested that while both female and male caregivers crossed traditional and stereotypical boundaries, different challenges were confronted by each gender. The experiences of the men who participated in the studies of Calasanti and Bowen and Russell refuted any contention that male caregivers merely mow the lawn, fix the car, wash the dog and pay the bills. Theirs are stories of adaptation, commitment, love and transition as illustrated in the words of 'Ron' who spoke of the "mixed blessing of having no sense of smell" (p. 13) and of 'Roman' who stated that six months of attending his wife's personal hygiene needs, "cured me of biting my nails" (p. 14).

Finally, in considering the transitional impact from different cultural perceptions, the study of Navab, Negarandeh and Peyrovi (2012) reported on the lived experiences of Iranian families. Introducing a theme of "captivity in the whirlpool of time" (p. 1080), the focus of family stories revolved around reminiscence of the past and fear of the future. There was no speaking of the 'now' time: implying that there was no acknowledging the pervading circumstances of the currency of experience.

3. Transitional change

Change in a caregiver's life can be significant: as illustrated in research outcomes reported by Varela, Varona, Anderson and Sansoni (2011). Participants expressed that they had little time to themselves and felt that their own social life was being impacted. It was also noted that participants expressed feeling emotionally drained: with the general consequences of impact being associated with physical health and subjective psychosocial well-being. Caregivers also shared feeling that they were at risk of not receiving support from others, while exposing themselves to depression and physical vulnerability. This was highlighted by Varela et al. to be of particular significance as cognitive and physical deterioration of the care receiver progressed and as associated behaviour became increasingly stressful for both caregiver and care receiver. Transitional changes also included significant increase in depressive symptoms, along with decreased immune function, decreased wound healing capacity and autonomic and neuroendocrine dysregulation: all worsening with increased stress. Sleep quality was also reported to be inadequate or insufficient, as caregivers were often wakened through the night by their care receivers. This resulted in the caregivers' experiencing sleeping issues that continued well after the Alzheimer's patient had moved out of home or had died. Caregivers advised that they found themselves sleeping better when they were able to take breaks and it was reported that the weaker the social support for the caregiver, the worse the sleep quality: the corollary being that the stronger the social support for the caregiver, the better the sleep quality and the subsequent ability to cope with the presenting challenges of each day.

4. Aspects of Impact: Stress response

Stressors have the potential to be multi-dimensional and significant, particularly when that 'Special Someone' develops high levels of psychosis (including delusions and hallucinations), mood disturbances and cognitive fluctuations. According to Flaskerud (2000) and Lee, McKeith, Mosimann, Ghosh-Nodyal and Thomas (2013), caring incurs significant levels of stress that may affect emotional, mental and physical well-being. Aspects of impact were reported in terms of changes to lifestyle and role functioning abilities, through disruption of interpersonal relationships, social life and work life. It was also noted in both studies (Flaskerud and Lee et al.), that stress also presented as having a flow on impact associated with increasing financial strain.

Wang (2013) drew particular attention to the notion of chronic stress associated and when comparing the burden of stress differentiation between caregivers who care for a loved one with dementia and caregivers who care for a loved one with depression, Leinonen, Korpisammai, Pulkkinen and Pukuri (2001) reported significant connection between low functioning capacity of the care receiver and stress burden of the caregiver.

Flaskerud (2000) referred to loneliness as having a complex relationship in the process of caregiving and she suggested one aspect of loneliness as being associated with social isolation stemming from the constancy of care: especially when the duration and intensity of care became great. Yan and Kwok (2011) also reported intensity of care and constancy of contact associated with co-residing as being significant factors in stress burden: to the point where they were deemed to be predictors in initiating both verbal and physical abuse towards the care recipient.

Lee, McKeith, Mosimann, Ghosh-Nodyal, and Thomas (2013) proffered the notion that loneliness could also stem from the loss of mutuality and reciprocity in the relationship with the care receiver due to the onset of functional dependence, cognitive decline and general weakness and pain. Lee et al. also suggested that stress could be related to the number of hours per week engaged in providing care, severity of cognitive impairment, relationship with the patient, demonstrated behaviours of the patient and support that was received.

5. Aspects of impact: loss and grieving

In considering the notion of a 'grief response', Ott, Sanders and Kelber (2007) presented a definition in terms of "reaction to the perception of loss with normative symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and a variety of physical symptoms that are unique to the individual" (p. 799). According to Ott et al., grief occurs when the safety and security that a person feels within a relationship becomes threatened. Ott et al. also posited the notion that despite the stress and strain that occurred between a caregiver and a care receiver, a bond existed that created an intense form of attachment and as the attachment changed as a result of disease progression, grief was the natural by-product.

Silverberg (2007) introduced a '**3-A**' grief intervention model for dementia caregivers and proposed that the model, '**A**cknowledge, **A**ssess, **A**ssist', enfranchised the caregiver's grief experience through **A**cknowledging, **A**ssessing and **A**ssisting in grief management. Silverberg explained that from the time symptoms began to insidiously emerge, it could take well over ten years for Alzheimer's disease to run its course. This timeline was also supported by Summers (2014), who proposed a time frame of four to ten years from diagnosis to end of life. Silverberg also made reference to the impact on the primary caregiver in terms of emotional and physiological experience, expressing that in addition to the crippling effect for those inflicted with Alzheimer's disease and Alzheimer's related dementias, this lengthy time frame could have debilitating impact on family, who were grieving the loss of the loved one they knew, pre onset.

In profiling the general experience of caregiver grief, Large and Slinger (2013) identified six emergent themes: namely, challenges of caregiving; losses and changes in the relationship; the role of dementia in grief; striving despite dementia; utilising social support and death as a relief from caregiving.

Sanders, Morano and Corley (2002) referenced the constancy of expressions of loss in statements given by caregivers, particularly male caregivers. Findings of Sanders et al. concurred with outcomes cited by Loos and Bowd (1997), who reported implications of the experience of loss and grief as expressed by participants in themes of loss associated with social and recreational activities, loss of personal freedom and control over life events, loss of well-being and loss of occupation. Participants in the Loos and Bowd study also expressed feelings of deep guilt, accompanied by an increased sense of loss, when their loved one was transferred to institutionalised care: expressing feelings that the well-being of their loved one was at risk.

6. The ripple effect

 When speaking of the impact of caring for a 'Special Someone' who has a diagnosis of Alzheimer's disease, it is important to consider just how far the impact is felt. Investigating the impact on extended family, Celdrán, Triadó and Villar (2011) reported that **adolescents** experienced a frequency of 15 varying emotions, as their relationship with a grandparent who had

dementia began to change. According to Celdrán et al., in general, the dementia process was seen as having a negative impact on relationships, eliciting fear and confusion. However, in some cases, there was seen to be potential for positive changes that were mainly related to the adolescent's ability to keep emotional contact, to express emotions and to be heard. In follow up studies to those of 2011, Celdrán, Villar and Triadó (2012) discovered that in situations where the grandparent moved into the grandchildren's home, the adolescents reported experiencing changes in their daily activities and identified mainly positive changes in the relationship they shared with their parents.

Similar impacts were reported by Hamill (2012) who advised that in her study, the trend seemed to be that the greater the affection adolescent grandchildren had towards their grandparent, the more they were inclined to offer help and the less concerned they seemed to be about the amount of time their parents gave in caring for their grandparents. Younger children also encounter Alzheimer's disease and Alzheimer's related dementia, particularly among grandparents and great-grandparents and in multi-generational households. Manthorpe (2005) warned that the needs of children may be easily overlooked. The advice was that younger children also needed information, needed to be encouraged to ask questions, needed to be reassured, needed to help to a level and scale with which they felt comfortable and above all, needed not to be overlooked and neglected.

7. Support

Support can be accessed in many places and according to Hogan and Schmidt (2002), social support is shown to facilitate healing as people transition, reconstruct their lives and find new meaning in life when major life events impact on the world that is, turning it upside down and inside out. In information provided by Alzheimer Europe (2014e), it was noted that as dementia progressively develops, so too do the needs of the person with the dementia and in turn, the needs of the caregiver. It was explained that while a particular solution may be helpful for a time, there is eventually a need to try different approaches. It was also explained that the caregiver can often feel alone and can tend to worry about coping. In support for the caregiver, it was suggested that it could be helpful to talk with others in a similar situation. The concept was posed that, often, personal accounts of others living with a care receiver who has dementia could be an invaluable support, normalising what is of the now and providing insight to what the future lived experience

might entail. It is advised that contact can be made through Alzheimer's Associations located throughout the world, with the mode of contact being by way of direct personal link with a local group or through social media crossing national and international boundaries.

Burns (2000) cited assistance available through primary health care providers in relation to dealing with patient behaviours and managing caregiver burden. Burns also suggested that caregivers need to be given written information on patient behaviour management, skills training and behaviour modification strategies to decrease stress burden. In addition, Burns referenced the lack of support provided by primary health care providers, attributing this deficit to lack of knowledge and associated time and resource constraints. In the study of Wackerbarth and Johnson (2002), caregivers identified the need for information concerning diagnosis and treatment and also information concerning legal and financial issues. Specific information about health plan coverage was also deemed to be important.

8. Barriers to support

Just as some caregivers experience personal growth in the midst of life changing events associated with the progressive debilitation of that 'Special Someone' who has a diagnosis of Alzheimer's disease, others can traverse an alternative pathway. These caregivers, become stuck in what Hogan and Schmidt (2002) referred to as "a crisis of meaning" (p. 616). In the quagmire of grief, there are those who experience a loss of self-confidence, become shrouded in a sense of unknowing and confused about who they are in the midst of what is perceived as being "both interpersonal and intrapersonal crises" (p. 629). Etters, Goodall and Harrison (2008) reported that appropriately tailored interventions can improve the health and well-being of both caregiver and care receiver. They also suggested that individually developed multicomponent interventions, including a diversity of services, tended to decrease burden, improve quality of life and enable caregivers to provide at-home care for longer periods, prior to institutionalisation.

However, while 'multicomponent interventions' are recommended, services are not readily accessible to all caregivers. According to data published by Varela, Varona, Anderson, and Sansoni (2011), the Italian Health Care System provided little support for caregivers and barriers to using

support services that were provided were said to include the attitude of health care professionals or health care assistants as well as out of pocket expenses that the caregiver had to pay. Similar barriers were reported for caregivers in Canada with Strain and Blanford (2002) advising that while quite a range of services were available for Canadian residents (for example, day centres, cleaning services, personal care services, in-home nursing services, home delivered meals, respite in hospitals or nursing homes), caregivers chose to not use the services for reasons that included reluctance to leave their loved one with a stranger, personal and/or cultural attitudes about care giving, lack of knowledge of available services, perceptions that services were too expensive and perceptions that their 'Special Someone' presented with too many behavioural and emotional problems.

A significant factor as to whether a caregiver is able to access support services, is geographic location. With specific reference to older rural carers, Winterton and Warburton (2010) cited a range of social barriers deemed to inhibit participation and also deemed to be exacerbated by residing in a rural area. Additional factors reported by Winterton and Warburton to be of significance in rural communities, were the highly valued virtues of stoicism and resilience.

Coming from a more personal perspective, Daly, McCarron, Higgins and McCallion (2013) made reference to caregivers' experiencing feelings of abandonment where, in the midst of social marginalisation and the implications associated with progressing dementia, aspects of what might be deemed to be of the 'normal' life-world, were frequently thrown away.

9. Coping strategies

According to Ross, Hollimand and Dixon (2003), coping is about identifying the most difficult aspects of caregiving, dealing with them and celebrating the benefits and growth opportunities. Coping is also said to be about resilience: discovering and engaging methods of successfully managing the demands of caring for a loved one who has Alzheimer's disease or Alzheimer's related dementia.

As explained in the report of Daly, McCarron, Higgins and McCallion (2013), coping is about "sustaining our place": moving from experiencing and interpreting threats to place to developing

and implementing actions that are aimed at sustaining place and overcoming risk of marginalisation and loss of social contact. It was suggested by Daly et al. that this is done through developing a toolkit of enabling factors that comprise protective, defensive and inter-relational strategies, conceptualised as "nurturative protecting" and "inter-relational labouring" (p. 505). Strategies employed, included confirmation and upholding respect for personhood, claiming place rather than becoming dependent on others to grant or bestow, prioritising needs of both care receiver and caregiver, working to preserve dignity, nurturing self and nurturing that 'Special Someone', acknowledging limitations and recognising that at times, there is the need to prioritise 'I' over 'You'. Participants in the Daly et al. study also addressed the benefits of holding hope, developing strategies to manage emotions, respite, contingency plans, constructing a support network inclusive of other caregivers who could identify with similar emotions and challenges and learning as much as possible about Alzheimer's disease and dementia.

A key aspect to coping was identified by Fortinsky, Kercher and Burant (2002), Gallagher, Ni Mhaolain, Crosby, Ryan, Lacey, Coen, Walsh, Coakley, Walsh, Cunningham and Lawlor (2011) and Semiatin, and O'Connor (2011) as 'self-efficacy': a notion that reflects the work of Bandura (1986) and is often referred to in every-day conversation as the 'self-fulfilling prophecy'. Fortinsky et al. proffered the notion that higher levels of self-efficacy are expected to lead to health-promoting behaviours and improved measures of physical and mental well-being for family caregivers of persons with Alzheimer's disease. For Gallagher et al., 'self-efficacy' is about prediction of carer burden and carer depression in relation to symptom management, emotion-focussed coping, dysfunctional coping levels, patient function and/or neuroticism in relation to anxiety, OCD or perceived somatic complaints without any real evidence of disease or ailment. For Semiatin and O'Connor, 'self-efficacy' is about influencing "the development of affective filters that influence whether life events are cognitively construed, represented and retrieved in an affectively benign or distressing manner" (p. 686). Self-efficacy could also be a significant factor in the functioning of what Donovan and Corcoran (2010) defined as "uplifted caregivers" (p. 592) who were identified as being less likely to live alone with the care receiver, as experiencing fewer symptoms of depression and as having lower levels of both objective (related to self) and subjective (related to significant others) stress burden factors. Donovan and Corcoran also referred to the key coping strategies

deployed by the 'uplifted', which included engagement in positive behaviours and making adjustments to attitudes.

10. Coping with abusive behavior

Reporting the results of a survey conducted in 2010, Alzheimer Europe (2014f) noted that 220 family carers of people with dementia identified as follows …

- Over one third of those surveyed reported experiencing significant abuse from the people they cared for.
- Those who reported abuse also reported a greater deterioration in the relationship.
- Dysfunctional coping strategies partially explained deterioration in relationship.

In a study conducted by Cooper, Selwood, Blanchard and Livingston (2010), over one-third of family caregiver participants reported significant abuse from the care recipient who had dementia and the abusive behaviours were reported as being a mix of verbal, psychological and physical orientations. It was noted that caregivers who reported more abuse also reported a greater deterioration in their relationship with the person with dementia and it was suggested by the authors that the extent to which caregivers used dysfunctional coping strategies could partially explain this incidence of abusive behaviour. Cooper et al. also suggested that some abusive behaviours may be indicators of neuropsychiatric symptoms, which are part of the dementia.

In keeping with this line of thought, VandeWeerd, Paveza, Walsh, and Corvin, (2013) observed that as Alzheimer's disease progresses, the risk of abuse by both care receiver and caregiver increases. For VandeWeerd et al., considering risk factor from a perspective of caregiver burden, poor functional and psychological health and difficulties in coping with higher levels of functional impairment, avenues for abuse prevention may lie in increased physical, occupational and assistive device therapies for both caregiver and care receiver. The rationale underpinning such intervention was reported to have emerged from studies showing that many older adults were acting significantly below their functional capacity, with or without any contributing impairment.

Ahn and Horgas (2013) and Abbey (2015) referred to the notion that demonstration of abusive behaviours could be in direct correlation with pain frequency, pain intensity and the increasing inability for the person with Alzheimer's or Alzheimer's related dementia to verbally express that he/she is in pain. It is explained by both sources that with advancing dementia, the care receiver gradually loses the ability to process information, so is less likely to express pain in typical ways. The presence of pain may be expressed through agitated, aggressive, disruptive and abusive behaviours because of the inability to appropriately verbalize the pain experience.

11. Maintaining dignity in the midst of chaos

According to *The Pocket Macquarie Dictionary* (Bernard, 1989), dignity has to do with the notion of worthiness. In considering the wants expressed by participants in the studies reviewed above (Living with dementia: Transitioning) and reflecting on these through a lens of basic needs gratification as defined by Glasser (1984, 1989, 1999), it could be said that dignity has to do with a sense of 'worthness'. It's about being seen as important, being valued, contributing, having a sense of worth (basic psychological need for personal power). It is about being trusted to offer advice and opinion and to make decisions (basic psychological need for freedom). It is about being cognitively and physically able to engage in creative pursuits and pleasurable activities (basic psychological need for fun). It is about being respected rather than ridiculed, being loved rather than pitied, being treated with empathy rather than with sympathy (basic psychological need for connection, love and belonging).

This notion of 'worthness' could also be seen in correlation with the notion of 'personhood', as discussed by Smebye and Kirkevold (2013) when they spoke of personhood as being "the right of every human being regardless of capacity" (p. 1). Smebye and Kirkevold drew on ideas posited by Buber (1958) who, close to 60 years ago, postulated the notion that all real living, is meeting with mutual acknowledgement of the uniqueness of the other. Thus, the dignity of personhood can be seen as a product of relationships with others and as such, has the capacity to be nurtured and strengthened or diminished and weakened.

Looking at the notion of 'worthness' through the lens of a transpersonal caring relationship as discussed by Watson (2008/1979), it is about caregiving that conveys concern for the inner life world of the care-receiver. It is about being present, in the moment, in a spirit that invites full loving-kindness and equanimity. It is about being able to read the moment and it is about a Self that is open, responsive and sensitive to what is happening and to what is emerging for the Other. It is about understanding and appreciating that a significant caring moment can be a turning point that affects both caregiver and care-receiver and that …

> radiates out beyond the moment, connecting with the universal field of infinity to which
> we all belong and in which we all dwell. Thus the moment lives on.

> Such an authentic spirit-to-spirit connection in a given moment transcends the personal
> ego level . . . and opens the (caregiver's) intelligent heart and head to what is really
> emerging and presenting in the moment. (Watson p. 79)

12. When it is time

As much as family want to care for their 'Special Someone', the time will inevitably come when admission to institutionalised care is what is needed to best serve the needs of both the loved one whose debilitation has now progressed to advanced dementia and the caregiver who is unable to meet the needs of the care receiver. This may be due to social isolation, impact of caregiving on caregivers' health, dementia related behaviours worsening with progression of cognitive impairment and loss of functionality, accelerated increase in daily care burden, need for more skilled care or a general need for more assistance linked with availability of support resources (Buhr, Kuchibhatla and Clipp, 2006; Sansoni, Anderson, Varolna and Varela, 2013; Sun, Durkin, Hilgeman, Harris, Gaugler, Wardian, Allen and Bergio, 2013 and Simard, 2014). It is noted that each of these factors, considered either singly or in combination, has the potential to escalate risk factored impact on caregivers' well-being as well as risk potentiality for caregivers to demonstrate harmful behaviours towards care receivers. According to Anderson et al, Buhr et al., Sansoni et al., Simard, Sun et al. and Varolna and Varela, whatever the circumstance, admission to a care facility can have significant impact on the caregiver who, either temporally or permanently, relinquishes to

professionals, the provision of control and care that has been a major part of their being and their doing, for some considerable period of time.

Tornatore and Grant (2002) and Tornatore and Grant (2004) reported in relation to the subjective stressors associated with transition to institutionalise. Bloomer, Digby, Tan, Crawford and Williams (2014) addressed the need for good communication between clinicians and caregivers and the need for the caregiver to be deemed the expert in the care of their loved one. Bloomer et al. also referenced the need for the caregiver to be included in decision-making processes and to be given emotional support throughout the period of time their loved one is a patient in the professional care facility, whether that be for respite, medical attention, residential transition or palliative care.

Unfortunately, the hospital/institutional experience does not always conform to the ideal, as recorded by Gierck (2015) who stated that, "Some days caring and niceness seem mutually exclusive" (p. 217). As also reported in the studies of Jurgens, Clissett, Gladman and Harwood (2012) and Spencer, Foster, Whittamore, Goldnerg and Harwood (2013), the experience of care was often negative, with key themes in the cycle of discontent being focussed through events, expectations and relationships with staff.

Dissatisfaction is not the exclusive domain of Australian families. It is of global significance. Experiences discussed by Jurgens, Clissett, Gladman and Harwood (2012) were cited as tending to lead to caregivers' becoming uncertain and suspicious which, in turn, led to periods of "hyper vigilant monitoring" (p. 1). Bloomer, Digby, Tan, Crawford, & Williams (2014) expressed similar thoughts to those expressed by Sansoni, Anderson, Varona and Varela, (2013); Sun, Durkin, Hilgeman, Garris, Gaugler, Wardain, Allen, and Burgio, (2013); Jurgens, Clissett, Gladman and Harwood (2012); Buhr, Kuchibhatla, and Clipp (2006); Tornatore and Grant (2004) and Tornatore and Grant (2002) all of whom suggested that patients with dementia and family caregivers needed support from professional staff, needed to be provided with information to reduce stress burden and to support caregiver health and well-being and needed to be considered as a unit. David Cooper (2014) referred to such considerations in terms of compassion, respect and dignity: "being with the

person and family . . . – one human being to another – seeing through the other person's eyes and empathizing with that person's pain, fear, joy, loss and sadness" (p. 11)

13. End of life

Relevant understanding of Alzheimer's disease, together with an awareness and acceptance of the progressive onset of dementia related degeneration and debilitation is deemed to be integral to appreciating aspects of impact when caring for that 'Special Someone' who has a diagnosis of Alzheimer's disease. Understanding, awareness and acceptance also demand that appropriate management of the stage of advanced dementia requires it to be recognized as a terminal condition that needs palliative care, the concept of which was born in the 1950s when, based on careful observation of dying patients, Dr Cicely Saunders first articulated her ideas about focusing on the care of the dying. Dr Saunders advocated that only an interdisciplinary team could relieve the total pain of a dying person, in the context of family (ASH Education, 2008). Simard (2014) noted that one of the biggest challenges facing professionals who counsel families whose loved one is living with advanced Alzheimer's related dementia, is that the condition is irreversible, is terminal and that decisions and goals of care need to change as the disease progresses. Three possible goals of care are named by Simard as "prolongation of life", "maintenance of function" and "comfort" (p. 169).

Kumar and Kuriakose (2013) claimed that interventions during the palliative stage need to be carefully chosen to ensure maintenance of the quality of life of the care receiver. They addressed the importance of advanced care planning whereby the individual's wishes are made clear in relation to the care they would like to receive at a time when they may no longer be able to make such decisions or be able to make their wishes known. Kumar and Kuriakose suggested that caregivers and other family members need to be educated and encouraged to actively participate in discussions related to aspects such as artificial nutrition, cardiopulmonary resuscitation and other medical interventions. They also suggested that critical aspects to consider include how invasive interventions can be, when it is doubtful as to the amount of benefit compared with the amount of associated discomfort. The question to be considered is, "Would this be what the patient would want if able to make the decision, judged on decision making actions of the past?"

In discussing research that focuses specifically on the notion of 'what the patient would want if able to make the decision, judged on decision making actions of the past', Van Der Steen, Van Soest-Poortvliet, Achterberg, Ribbe and De Vet (2011) assessed family perceptions of the preferences of dementia patients regarding end-of-life wishes about death and dying. Two specific areas deemed to be most relevant were 'treatment preferences' and 'preparation for end of life': generally deemed to be the most significant conditions associated with a "good death" (p. 219). According to relatives, treatment preferences embodied maintaining dignity and freedom from pain, with particular reference being made to bladder and bowel control.

End of life preparation covers a diversity of aspects, including costs, means to end life, talking about feelings and spiritual counselling. In the study of Van Der Steen, Van Soest-Poortvliet, Achterberg, Ribbe, and De Vet (2011), it was deemed important to spend time with family and in situations where pets were deemed to hold a significant place in the family, it was also deemed to be important for the dying patient to be able to spend time with a much loved pet. Spiritual caregiving was reported as being relatively unimportant in the overall priorities presented in the study and in responses from approximately half the participants of the study of Van Der Steen et al., family were reported as being generally unfamiliar with their loved one's feelings about fear of dying and preference for dying when conscious or unconscious: a condition of major relevance for palliative care sedation. This sense of unknowing was not part of Michele Gierck's story as she shared her experience with her mother …

> For weeks I've been worried about how Mum can die when she's so fearful of it. But today, she's making that transition. My mother certainly has pain in her head, and there are moments of wanting to hang on, but there's also a peacefulness. There is no longer fear of what beckons. She's slowly slipping into the next stage of her journey which each of us must take alone. (Gierck, 2015, p. 231).

Reflecting on the expressions of Kumar and Kuriakose (2013) in the light of information emerging from the end-of-life survey conducted by Alzheimer's Australia (2014b), it seems appropriate to conclude this literature review with words taken from the ASH Education Book (2008), which state …

Palliative medicine is the continuation of the long struggle to accept life on its own terms, honestly and openly. Taking its place in academic medicine, this new subspecialty will enable future generations of physicians to gain generalist-level palliative medicine skills while advancing knowledge in the field and fulfilling our promise to patients and their families that we will not abandon them when our treatments fail and that, at all times, we will do all we can to relieve their suffering. (p. 465)

Conclusion

As the prevalence of Alzheimer's disease increases and as the residential-centering of caregiving continues, the spread of family experiences of a loved one's suffering will rise. We understand less of the complex social and personal experience than we do of the documented rise of Alzheimer's disease in Australia. Review of the literature traced the pre-diagnosis to death trajectory in relation to 'The impact of caring for a 'Special Someone' who has a diagnosis of Alzheimer's disease' and was focused through a conceptual framework that encompassed 13 key themes of the caregiver journey across the trajectory of caregiving. Transitional changes for both care receiver and caregiver introduced the review which discussed a diversity of complexities embodied in the social construct of caregiving. No element of lifestyle escapes impact as the trajectory of care is traversed and as degenerative dysfunction erodes life as it was, pre-Alzheimer's.

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The Correlation between sound sensitivity and affective reactivity of nurses in Jakarta: A Pilot Study

Georgiana Claudie & Karel Karsten Himawan

Contact
Karel Karsten Himawan
Faculty of Psychology,
Universitas Pelita Harapan
Jl. M.H. Thamrin Boulevard, Lippo Karawaci
Tangerang 15811 – Indonesia
karel.karsten@uph.edu

Abstract

The aim of this study is to examine the correlation between subjective sound sensitivity and irritability toward elevated sound emissions in hospitals, resulting from a sharp increase in human activity following the Social Security Health Benefit (*BPJS Kesehatan*) program in Jakarta; particularly among nursing staff who constantly experience intense work-related stress. Nurses (n=101) assigned in inpatient wards completed the Khalfa Hyperacusis Questionnaire and Brief Affective Reactivity Scale as measurements. Results showed a significant correlation between sensitivity to noise and affective reactivity (irritability) ($p<0.05$), as well as correlations to a specific dimension of sound sensitivity and several demographic characteristics. It was indicated that exposure to noise may increase affective reactivity (irritability) or that being in an irritable mood worsens the perception of sound. Other mediating factors might also exist to report individual differences relating to either variable, such as personality traits, threshold differences, appraisal processes, and perception of crowd dynamics.

Keywords: noise, sound sensitivity, nurses, Jakarta

Introduction

Establishing physically favorable health care environments is a critical process in health administration. This process is needed to understand the functioning and recovery of hospital occupants, as health care workers are groups of employees who frequently experience exposure to stressors and health hazards (Maguire, et al., 2013; Imam, et al., 2013). The types of stressors or hazards are categorized into tangible (e.g. medical and biohazard waste) and intangible forms (e.g. psychosocial work-related issues), and the complexity of work characteristics may increase the experience of stressful labor situations when it interacts with such stressors.

Amid human service and care workers, nursing is a profession that meets the criteria of experiencing intense work-related stress, as they are demanded to be physically and emotionally involved in their duties (Ribeiro, et al., 2014). They are prone to changes in healthcare environments from the increasing demand for medical care resulting from population growth, progression of modern medical technology and its effect on patient turnover, the need to master advanced equipment, and other changes due to development-related factors (Tsara, et al., 2008; Imam, et al., 2013). Imam et al. (2013) provided additional stressors originating from occupational hazards being ergonomic (mechanical operations), chemical (solid and liquid matter), biological (urine, bacteria, viruses), psychosocial (mental and social stress), and physical hazards (noise, temperature, lighting, radiation).

To account for the changes in healthcare environments, a recent prevailing phenomenon in Indonesia is the sharp increase of patients with *BPJS Kesehatan* (social security health benefit) cards as part of the *Jaminan Kesehatan Nasional* (National Health Security) program established in January 2014. The distribution of the *BPJS Kesehatan* cards has caused a 100% increase of a hospital's regular patient intake, causing nurses to report distress from sudden work overload and the disarray of activities during patient administration (Zahra, 2014). Reports from nurses may be explained by the discrepancy between work stress, work demands and pay rate, however, what appear to be less introduced to an urban context are unnoticed variables in hospital environments.

A particular feature of the hospital environment following this development is the acoustic atmosphere within the hospital area. Corresponding to this event, Ryherd et al. (2011) asserted how a variety of sound sources occupy many areas of hospitals as activities prolong throughout the day, primarily when facilities are located within densely populated areas. Seeing that noise is an occupational hazard that holds the potential to risk physical and psychological health, it may influence the quality of service provided by health care personnel (Ryherd et al. 2011; Khademi, et al., 2011). As an unnoticed component of the hospital environment, sound emissions following increased patient intake is a potential concern for research.

The World Health Organization has addressed the problem of noise pollution by understanding the threat noise poises upon short and long-term effects on health and well-being, particularly when noise imposes greater risks toward certain vulnerable groups; healthcare workers, alongside children and the elderly (Berglund, et al., 1999). Indonesia's Occupational Safety and Health regulations also support the necessity to prevent and control the advancement of many types of environmental hazard including noise (Kementrian ESDM, n.d.). Hospitals in Jakarta are not silent work places, as many departments within a hospital are exposed to certain intensities of noise that may exceed sound levels determined by OSH regulations (Kementrian ESDM, n.d.). As the capital of Indonesia and similar to other major capital cities, Jakarta's population density of 9.7 million citizens causes a relay of intra-city developmental effects, and therefore inner city hospitals may find noise sources as an extreme nuisance (Badan Pusat Statistik, 2010).

As both auditory and non-auditory effects of noise may occur when noise is intensified, auditory loss or marked sound tolerance is one of the most common results of noise exposure, as functional changes within the central auditory system occur due to increased sensitivity of auditory cortex neurons (Sun, et al. 2012). From a non-auditory standpoint, Cohen, et al. (1986) who conducted field studies on physical stressors stated that uncontrollable noise is generally stressful and may cause shifts in task performance and lowered motivation. However, prior to hearing loss, individuals must have different levels of sensitivity toward sound as enhanced responses to acoustic stimuli occur. Those with lower tolerance are demanded to adjust their psychological states in noisy situations to reduce discomfort (Stansfeld & Matheson, 2003), which means that cognitive and emotional perceptions to noise are transformed into physiological stress responses (Piazza, et al.,

2013). In this sense, individuals who are more sensitized toward sound do not have more superior hearing, but they may have lower thresholds for stress reactivity and emotional reactions to stressors as hospital activity noise increases (Hill, Billington, & Krägeloh, 2014).

The increase of acoustic stimuli should not cause individuals to be at risk for irritability since loudness tolerance is correlated with emotional states and anxiety (Khalfa, et al., 2001). A common response to excessive sound is irritability, and in short, irritability is a state of annoyance that is shown through temper outbursts and may be indicative of emotional difficulties (Stringaris, 2012), although not all environmental stressors can elicit irritability when mediated by appraisal processes on perception of the stimulus itself. From an employment perspective, when emotional states are compromised, abatements in many areas of work performance might occur as seen through a decline in empathy, involvement, concentration, and interest thus contributing in affect reactivity (Fang, et al., 2008). The urgency to assess manifested affective reactions due to increased acoustic stimuli in Jakarta hospitals with *BPJS Kesehatan* affiliations is necessary to shield nursing staff, and patients respectively, from a specific hospital hazard; noise.

This study aims to investigate whether a significant correlation exists between sound sensitivity and affective reactivity (measured through irritability) within nursing groups across Jakarta following the *BPJS Kesehatan* program since 2014. When physical hospital hazards pose as threats and trigger affect reactivity, specific dimensions (functional, social, or emotional) of sound sensitivity can be affected and therefore a bidirectional relationship between affective states and stressors might appear.

Methods

Participants

Participants consist of 101 nurses from one state-operated hospital in South Jakarta that administrates social security health benefits (*BPJS Kesehatan*), with an age range between 18 to 55 years (M=26.95, SD=6.91). All subjects signed an anonymity and informed consent form to participate in the study. The name of the establishment is undisclosed by request of the hospital's Research and Development Department for ethical considerations.

Instruments

The Khalfa Hyperacusis Questionnaire (HQ) (Khalfa, et al., 2001) was used to measure subjective sound sensitivity. The Khalfa HQ was initially developed to detect clinical hyperacusis (extreme sound sensitivity), however, the instrument can be used to detect general discomfort toward sound through the levels of mild to major distress from the instrument's score gradations. The instrument consists of 3 dimensions; attentional, social, and emotional. These dimensions are not scored separately – 14 items (given on a 4 point rating scale) produce a unified score. The maximum score for the Khalfa Hyperacusis Questionnaire is 42. To differentiate the influence of their work and the possibility of developing irritability and sound sensitivity, the Khalfa HQ places three preliminary questions (Q1, Q2, Q3) in the first section of the questionnaire to identify history of hearing damage or noise exposure that may relate to sensitivity from exposure. Two non-HQ closing questions (Q4, Q5) were placed in the end of the questionnaire to measure current perception of hospital noise, as well as the level of personal disturbance due to environmental noise.

The Brief Affective Reactivity Scale (AR) was developed to measure the degree of irritability without measuring aggressive tendencies or hostile behavior through threshold, frequency of feelings, and durations of angry reactions. It is a self-report measure based on irritability symptoms of mood disorders in the DSM-V, as well as theoretical constructs of the State Trait Anger Expression Inventory - 2 (Spielberger, 1988) and Affective Reactivity Index (Stringaris, et al., 2012). The BARS initially consisted of 15 items given on a 4-point rating scale, however, subsequent to tryouts on intern nurses at the author's university hospital, and consistent score results with the field samples, 4 items with low item validity were removed, leaving 11 items for statistical analysis. The BARS' maximum score after item removal is 33. Item validity and internal consistency of the BARS is presented in Table 1.

Table 1.

Validity and Reliability of the Brief Affective Reactivity Scale

Samples	n	Aspect (Item)	Item Total	Item Validity	Cronbach's α
Try out (before item removal)	37	Frequency (1,2,3,4,5)	5	.360 - .601	.677
		Intensity (6,7,8,9,10)	5	-.120 - .501	
		Duration (11,12,13,14,15)	5	.139 - .273	
Try out (after item removal)	37	Frequency (1,2,3,4,5)	5	.508 - .670	.806
		Intensity (6,7,10)	3	.409 - .539	
		Duration (12)	1	.204	
Field (before item removal)	101	Frequency (1,2,3,4,5)	5	.355 - .563	.736
		Intensity (6,7,8,9,10)	5	-.206 - .524	
		Duration (11,12,13,14,15)	5	.148 - .513	
Field (after item removal)	101	Frequency (1,2,3,4,5)	5	536 - .640	.853
		Intensity (6,7,8,10)	4	.480 - .576	
		Duration (11,12)	2	.476 - .576	

Permission to use the Khalfa HQ was received through electronic mail. Adaptations were made for the Khalfa HQ by forward and back translating the items into Bahasa Indonesia with the assistance of two native English speakers from a Jakarta-based language institution.

Our data showed that both instruments have adequate psychometric properties from field sample analyses. Only 4 items in the BARS held corrected item-total correlation values below .20. These 4 items were removed to generate greater internal consistency seeing that the amount of samples obtained (n=101) met the requirements for item removal (5 x N items) (Cohen et al., 2013). Cronbach's α is also satisfactory for both instruments; the Khalfa HQ reaches .884, and .853 for the AR. The following table represents the descriptive statistics for both instruments. Greater scores in the Khalfa HQ indicate greater sound sensitivity, and greater degrees of irritability in the AR scale.

Table 2.

Psychometric Description of the Instruments

Instrument	n	Min. Score	Max. Score	Mean	SD	Cronbach's α
Hyperacusis Questionnaire (HQ)	101	2	28	11.36	6.21	0.884
Brief Affective Reactivity Scale (AR)	101	0	22	5.59	4.62	0.853

Design

This study applied a cross sectional design to verify the significance of the relationship between the two variables. The significance level is set at 0.05. Items are considered reliable if Cronbach's alpha is greater than .60 and internal validity is based on the corrected item-total correlation value $>.20$ (Latan & Temalagi, 2013).

Statistical Analysis

Data was processed with SPSS version 20. Analysis of supplementary data was generated with analysis of variance and Mann-Whitney tests for age, gender, residency, ward of placement, and BARS and HQ scores.

Results

Descriptive Statistics

Most of the participants are women (92.07%) with the mean age of 26.95 years old. Regarding the educational level, 99% of the participants are graduated from the diploma level in the nurse education. Table 3 summarized the more complete characteristic of the participants.

Table 3.

Demographic Characteristics of Participants

Demography	Category	n	%	Mean
Age		101		26.95
Sex	Male	8	7.92	
	Female	93	92.07	
Education	Diploma (*Ahli Madya)*	100	99	
	Bachelor (*Ners*)	1	1	
	Master (*Magister*)	-	-	
	Doctoral (*Doktor*)	-	-	
	Undisclosed	-	-	
Residency	East Jakarta	8	7.92	
	South Jakarta	53	52.47	
	Greater area (*Depok, Tangerang, Bekasi)*	34	33.66	
	Undisclosed	6	5.9	
Ward of Placement	VIP	19	18.8	
	First Class	19	18.8	
	Second Class	25	24.75	
	Third Class	16	15.84	
	Maternity & Post natal	9	8.9	
	Pediatric (inpatient)	13	12.87	
Work duration (years)	-	101	-	5.79

Normality Tests

The one-sample Kolmogorov-Smirnov test was used to conclude the normality of distribution. The purpose is to further determine the correlation method to test the hypotheses. The level of significance used is .05, meaning that a 5% error rate is allowed. Data can be processed with parametric tests if $p>0.05$. The normality test is presented in the following table.

Table 4.

K-S Normality Tests for Each Variable

Variable	Sig.	Conclusion

Sound sensitivity (Khalfa HQ)	.063	Normally distributed
Irritability (BARS)	.013	Not normally distributed

Hypotheses Test

Spearman's rho (ρ) showed a significant correlation between sound sensitivity and affective reactivity among the respondents as measured by the BARS and HQ (ρ= .700, p= .000). In addition, the preliminary questions reveal that 38.6% of nurses (n=39) reported that they currently feel exposed to noise (**Q1**), while 65.3% (n=66) are less tolerant toward noise compared to previous years (**Q2**), and 2.9% (n=3) nurses have a history of hearing problem (two subjects reported a history of otitis media and cerumen buildup, while the other did not disclose the hearing problem type) (**Q3**). It was assumed that current perception toward noise exposure (Q1), current tolerance of noise compared to previous years (Q2), and history of hearing problems (Q3) will yield different HQ scores. Only those who answered 'yes' to Q1 produce greater sound sensitivity scores (U=911.5, $p<0.05$), compared to those who responded 'yes' to Q2 and Q3. However, no significant correlation between nurses who provided higher ratings to **Q4** and HQ scores ($p>0.05$), neither with **Q5** and HQ scores ($p>0.05$).

Table 4.

Summary of supplementary data

Variable	Spearman's ρ	Mann-Whitney U	Anova *F*
1. Attention dimension and AR	.639**	-	-
2. Social dimension and AR	.662**	-	-
3. Emotional dimension and AR	.533**	-	-
4. Age and AR	-0.127	-	-
5. Age and HQ	0.893	-	-
6. Gender and AR	-	308	-
7. Gender and HQ	-	140*	-
8. Residence and HQ	-	-	2.902*
9. Ward of Placement and HQ	-	-	2.865**

Note: all tests are two-tailed. *p<0.05 **p<0.02 (AR: affective reactivity or irritability, HQ: hyperacusis questionnaire or sound sensitivity).

To provide comparisons with the base literature, gender and age are demographic variables assumed to correlate with sound sensitivity and irritability. The AR scores were significantly correlated to the attentional dimension (ρ= .639, p<0.01), social dimension (ρ= .662, p<0.01), and emotional

dimension (ρ= .553, p<0.01). However, there is no significant correlation between the age of nurses and HQ scores (ρ=.893, p>0.05). Age was also assumed to correlate with the social dimension due to maturation and loss of habituation to noise exposure, yet results only yielded a significant and negative correlation between age and attention (ρ=-.198, p=0.048), but not with the social dimension (p=0.842), and emotional dimension (p=0.681). A significant HQ score difference was found with males producing greater sound sensitivity (HQ) scores compared to females (p=0.03), but there is no significant AR score (irritability) difference between males and females (p=0.419) despite female respondents exceeding the number of males.

There exists a significant mean difference of sound sensitivity (HQ) scores and ward of placement, whereby nurses stationed in the pediatric ward tend to have greater sound sensitivity (F=2.865, p=.019) compared to nurses in the first class, second class, maternity/post-natal, and VIP ward, with $p \leq 0.05$ respectively for each ward, but no differences with the third class ward nurses (p=0.038). In addition, first class and pediatric ward nurses have greater irritability (AR) scores compared to other wards ($p \leq 0.05$). Finally, based on residence and commuting distance, nurses who live in South Jakarta produced greater irritability (AR) scores compared to those living in East Jakarta (p=0.048).

As this study reveals a correlation between aspects of sound sensitivity and irritability, the researcher asked for brief, unstructured testimonials from nurses in several stations regarding their perception of the changing hospital environment since the *BPJS Kesehatan* program establishment. The researcher discovered that nurses have greater concern relating to the disorderly environment in inpatient units during visiting hours rather than the intensity of noise produced. Inpatient visitors who visit in large groups were reported to ignore the nurse's reprimand to lower their voices. On the other hand, nurses in the outpatient clinic are concerned with the lack of order during administration and that patients were not occupying waiting areas in an organized manner. Nurse's perception of noise may have more to do with the visitor behavior and its impact on patient discomfort rather than the intensity of noise itself, primarily with the multitude of visitors and patients since the *BPJS Kesehatan* program. In this case, crowd dynamics can be considered a confounding variable as appraisal processes (negative affect) toward the environment can be separated from sound sensitivity itself. For example, certain departments in a hospital (e.g. radiology, CAT scan, and MRI

wards) may be filled with patients but noise emissions are lower compared to the central outpatient clinic. Therefore the existence of a crowded, but less noisy environment will affect the perception of noise severity.

Discussion

The main objective of this study is to determine whether a significant correlation exists between sound sensitivity and irritability among nurses in a heavily occupied *BPJS Kesehatan* hospital. Environmental factors are assumed to increase sound sensitivity based on the intensity and source of sound (Khalfa, et al. 2001), and irritable mood is assumed to worsen the perception of sound as it elicits annoyance toward the stimulus or event that produces the stimulus (Frijda, 2009). Based on the Khalfa et al. (2001) study results on the development of the Hyperacusis Questionnaire, exposure to noise may be one of the many, though not definite, factors as to why sound sensitivity increases. We must take into account that individual differences (e.g. personality, appraisal processes, age) may be risk factors to respond to increasing stimuli (Topf, 2000). The findings in this study corresponds to Ramirez' et al. (2004) study, revealing a significant correlation between individual sensitivity to sound and feeling components, particularly in aspects of anger state and trait. To better explain the relationship of sound sensitivity and affective reactivity, mediating variables may exist to determine the significance of the relationship that is not included in this study. Such mediating variables that co-exist in sound sensitivity and affective reactivity in previous studies are personality traits (e.g. neuroticism and introversion) (Hill, Billington, & Kräegloh, 2014), pre-existing appraisal processes (negative affect) (Piazza, et al., 2013), and perception of sound during stressor and non-stressor days (Khalfa, et al., 2001). For example, to express either variable, an individual with high irritability (AR) scores may be high in trait neuroticism and possess negative attitudes toward the acoustic environment. Individuals with these characteristics demonstrate a condition in which a person has lower reactivity thresholds toward stimulus when they are in an irritable mood (Västfjäll, 2002), further asserting that acoustic stimulus from human activity is perceived as annoying or threatening. In addition, stress that is generated from environmental noise may induce particular affective reactions or modify other aspects of adaptive functioning, such as cognitive processes in support of various work-related performances, seen through the attentional dimension scores of the Hyperacusis Questionnaire (Khalfa, et al., 2001).

The preliminary questions in the Khalfa Hyperacusis Questionnaire were also included in the translated questionnaire. Significance was seen only for Question 1 ($p<0.05$), in which HQ scores were higher for those who answered 'yes', but no significance found for 'yes' responses to Question 2 and 3. Habituation processes might be an explanation as to why 65.3% of respondents have felt (or currently feel) exposed to noise to (Question 2) but have lower HQ scores. In general, habituation occurs when an arousal reaction is suppressed by inhibitory mechanisms when a stimulus is repeatedly anticipated (Stein, 1966), meaning that noise levels might be expected during certain times of the day and have no direct consequence to hearing processes. Furthermore, the final questions in the booklet were placed to reveal the directional relationship between higher ratings of noise perception and disturbance levels toward HQ scores. No statistical significance was found between Questions 4 and 5 toward the HQ scores ($p>0.05$). However, a central tendency effect is found seeing that 40.6% of the responses ($n=41$) indicated that they perceived the hospital environment over the past 6 months as moderately noisy, and 45.5% rated moderate disturbance due to the noise conditions. However, the HQ scores cannot rely entirely on the perception and level of disturbance from noise, as the aforementioned factors such as negative affect toward sound, appraisal processes, and intrapersonal traits may affect reported HQ scores.

An analysis of variance (ANOVA) was conducted to detect the difference of human activity in different wards and how it may influence both sound sensitivity (HQ) and irritability (AR) scores. A few significant effects were found; the pediatric ward nurses produced greater scores compared to nurses in other wards i.e. second-class, VIP, maternity/post natal, and VIP ($p>0.05$) except nurses assigned in the third class wards. Based on existing reports following the *BPJS Kesehatan* patient rise (e.g. Zahra, 2014; Surya, 2015), noise levels generally occupy the outpatient clinic where administration takes place, also third class wards where the number and placement of beds trigger the lack of noise control compared to first class or VIP wards. Patients in these third class wards receive visitors with no partitioned spaces. Significance was also found in AR scores being greater among pediatric and first-class nurses compared to second-class nurses ($p>0.05$), showing consistency with the HQ score differences. From a literary perspective, the similarities of HQ and AR scores between the third class and pediatric ward is unknown, as studies generally show greater

criticism on sound levels in intensive care units and accident/emergency rooms compared to inpatient wards (e.g. Khademi, et al., 2011; Konkani & Oakley, 2012; Ryherd et al., 2011). For example, the findings by Konkani and Oakley (2012) from critical care units are centered in high intensity medical equipment, ventilation systems, and staff activity rather than visitor activity. A possible explanation for the ward placement findings is that nurses in this group have similar intrapersonal characteristics in response to ambient stressors and that the pediatric inpatient ward in this particular hospital comprises of VIP, first, second, and third class beds. This could mean that responses to noise in the pediatric ward is mediated by reaction to varying work stress relating to parental demands in caring for children, and the management of health care for children as being more multifaceted compared to caring for adults.

In the context of other demographic variables, it is assumed that certain factors such as age and gender might influence sound sensitivity among females of older age as they have been more exposed to acoustic stimuli (Khalfa et al., 2001). However, results show that there is only a significant correlation between age and overall sound sensitivity scores (p>0.05), and a significant and weak correlation only with the attentional dimension of the HQ (ρ=-.198, p=0.048). This finding might reveal that certain age groups have greater awareness to noise levels and the need to avoid it in order to maintain cognitive functioning, and that age may pose as a significant risk factor to stressor reactivity (Ramirez, et al., 2004). Furthermore, gender differences were significant with males having higher mean ranks in HQ scores (p=.003). Contradicting the imbalance of male and female respondents, it was expected that female respondents would produce greater AR scores compared to males. Socio-biological developments might account for these differences, meaning that males express their discomfort toward sound more readily than the females (Ramirez, et al. 2004).

Residence is another factor for analysis, seeing that 33.6% of nurses reside in Jakarta's greater area and require greater commuting distance. It was assumed that nurses who take longer travel hours might be more exposed to noise from high traffic roads compared to those who live closer to the hospital of employment, which may exacerbate their perception of noise in their respective wards. Our findings show that nurses residing in South Jakarta and the greater are have greater mean differences in irritability scores compared to those residing in East Jakarta. Population density in

each area was assumed to account for these findings, however, population differences for each square kilometer was not found. The statistical figure for South Jakarta inhabitants being fewer compared to East Jakarta and Jakarta's greater area cannot be a reliable source to account for these differences (Badan Pusat Statistik Kota Administrasi Jakarta Selatan, 2013), therefore the researcher considers population density around the South Jakarta hospital as the basis for exposure, not solely on travel distance or domicile. In essence, sound sensitivity differences based on residence are inconclusive.

Conclusion

The effects of living in a noisy work environment in Jakarta reflect the lack of anti-noise regulations and its correspondence to population density, hence changes in the work environment is more likely to improve a person's overall health rather than the particular organ that is being affected (Chepesiuk, 2005). The evaluation of the acoustic environment and the responses of its occupants can be acknowledged to provide substantial bases for effective hospital environment management. The key finding in this research is that an increase in hospital activity noise may be a determinant of discomfort toward sound and irritability toward major sound sources. Key components to adjust in future research are the sample size and hospital location, occupational context, and other intrapersonal measurable variables. The Brief Affective Reactivity Scale will require further validation before use in future studies. Other hospitals with greater and lower visitor capacity may also affect mood states and the perception of acoustics; therefore comparisons can be made based on hospital facility size and location. The generalizability of the outcomes are confined only to the sample of nurses collected in this South Jakarta hospital only, not towards the general nurse population or population of healthy adults exposed to noise originating from human activity. It is also not possible to generalize relationships between sound sensitivity and irritability when other factors are not included in analyses, such as personality traits and lifestyle, but these findings may account for possible changes due to increasing hospital noise levels.

Investigations on other occupational sectors that involve intense employee–noise interaction can also be conducted to provide comparative analysis and help identify the risks that noise poses for workers (e.g. airport ground staff, construction workers, and nursery teachers). Other stimulus forms and its effect on irritability in work settings can also be included to assess mood changes,

such as lighting and temperature. Lastly, other variables that may contribute to the onset of irritable mood and sound sensitivity other than demographic factors can be included. Such factors can be subjective health complaints, pre-existing negative affect that worsens the perception of stimuli, personality traits (neuroticism and introversion) that correlates with reactions to stimulus, and personal negative attitudes during stressful and non-stressful days.

Recommendation

A practical recommendation would be to raise public awareness to comply with crowd control regulations in hospital settings, such as limiting the number of inpatient visitors per visiting hour with reinforced assistance of hospital security personnel. Changes in the ambience of inpatient wards and outpatient clinics can also be done with soothing music played during daytime to induce calming effects for nurse's sound perception and mood. The Occupational Safety and Health board (*Keselamatan dan Kesehatan Kerja*) in Indonesia should study building design modifications and interventions to reduce noise produced from human activity, or to evaluate crowd dynamics that pose as stressors for health care staff. This particular hospital may also implement stress reduction programs for nurses through mindful meditation designed to enhance well-being, increase resilience, reduce anxiety and exhaustion, and overcome performance issues. These programs are aimed at counteracting the effect of stimulus overload upon the nervous system and can be incorporated to daily schedules to achieve adjusted responses to stressors.

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