THE CARER PERSONA: MASKING INDIVIDUAL IDENTITIES

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ABSTRACT

According to Jungian theory, 'persona' is a concept reflecting a compromise between the individual and society. In mediating between a person's subjective inner world and the external social world, the persona represents a generalised idea of the self which builds up from experiences of interacting with society. Such reflections of self-identity can therefore develop across multiple domains of a person's life, culminating in understandings of self in a variety of specific roles. The existence of multiple personas can be clearly demonstrated in the context of people providing unpaid care for a family member or friend who has a disability, mental illness, chronic condition, or who is frail. Carers are likely to possess multiple roles as an individual, existing across various social and personal domains. This paper argues that in caring for loved one, a compromise takes place between individual selves and the social caring role. That is, the 'carer persona' can mask a carer's individual identities and their associated needs. The potential complexity of caring roles is therefore explored, with an emphasis on acknowledging the personal needs and identities of carers beyond their caring roles. This acknowledgment has implications for service delivery and policy development regarding carers and those for whom they care.

KEY WORDS

persona, carers, identity, recognition, support

PERSONA

Persona, as defined by Jungian psychology, is a compromise between the individual and society (Jung "Collected Works Vol. 7" 156). This compromise represents a potential conflict between who a person is and who they believe they ought to appear to be. The persona may therefore be argued to represent a public presentation of an individual that reflects who others think he/she is (and who he/she thinks she is) as opposed to who he/she actually is, i.e., a social face or façade. This serves the simultaneous functions of hiding one's 'true self' and making desired impressions on others, while also enabling a person to avoid the emotional closeness or vulnerability that comes with revealing the entirety of the self (Hudson 56). Due to its function of hiding the 'true self', the concept of 'persona' has been likened to a mask – a social role that a person employs to mediate between the inner world of the self and the external social world (Hudson 56). As such, Jung implies that the persona is largely moulded by society ("Collected

Works Vol. 7" 41). In likening the persona to a mask, an essence of 'falsehood' permeates representations of persona. As opposed to a true representation of the inner self, the persona is thought to be a constructed identity that is built up based on social interactions and expectations of others (Jung "Collected Works Vol. 6" 218), enabling people to present themselves to others in a fashion that they believe they should.

Jung suggests that the persona exists for the convenience of the individual in adapting to his/her broader social environment ("Collected Works Vol. 6" 466). Any role a person undertakes brings certain expectations regarding how to behave within that role, that is, a role specific persona. By adapting to these expectations, the persona is the mechanism by which an individual complies with his/her social reality, as opposed to the 'true' nature of the self (Hudson 57). This compliance with social expectations over the self represents the 'falsehood' that underpins the persona.

Since the persona is constructed through cumulative social experiences, these projections of self can develop across a wide range of domains in a person's life, such as family, work, and the wider community. As well as originating through these various social interactions, the persona can be seen to develop into a series of specific roles or identities across multiple contexts (Hudson 56). While an individual may identify with many different roles in the course of his/her life and social experience, these various identities can each only ever comprise a segment of that person's overall self, not its entirety. Understanding the persona in terms of a relationship with the social world suggests that it is possible to take on new social identities or withdraw from existing ones under changing circumstances and contexts. For example, a person who identifies with a 'professional' persona in the workplace may then identify with a 'parent' persona upon returning home to the family environment, and will behave accordingly in each situation. The persona can thus be seen as a series of selfconstrued identities or compromises between the 'true' self and different contextual environments, developing into multiple specific roles and patterns of behaviour as the individual interacts with and adapts to his/her social world (Hudson 56). In this way, the persona may be interpreted as a unified public identity that masks a series of individual identities, each of whom has their own individual needs. While no persona can accurately reflect the full extent of a person's individuality, it is important that it is flexible enough to allow a person to adapt to the multiple roles played across the breadth of social experience.

While useful in directing an individual's behaviour and interaction with social environments, there can be danger in identifying too closely with a persona, such as losing sight of the 'true' self. In doing so, a person is likely to think, feel and do what is expected of the predetermined social role that is represented by the persona to the extent that his/her personality begins to equate to the persona to the exclusion of all other aspects of self (Jung "Collected Works Vol. 7" 194; Sharp 58). Those who identify with their persona do not acknowledge any aspect of themselves beyond their social roles to the detriment of their 'true' self's needs. The persona may then become more than a context-specific role, but overtakes patterns of behaviour in all situations.

CARERS' MULTIPLE IDENTITIES

The existence of multiple roles and identities can be clearly demonstrated in the example of people providing unpaid care and support for a family member or friend who has a disability, mental illness, serious or terminal illness, chronic condition, or who is frail. As will be elaborated in the sections that follow, carers are likely to identify with a vast range of roles throughout the course of their caring and broader life experiences. For example, carers may undertake roles related to their various family relationships, employment situation, or other

aspects of their personal identities. Furthermore, depending on the individual caring situation, multiple personas are likely to exist as carers present themselves to the social world in different contexts. Carers are not a homogenous group, with significant diversity existing across individual carers, relationships, and the situations in which they care. Carers exist in all communities and population subgroups, including Aboriginal communities, those of culturally and linguistically diverse backgrounds, amongst gendered and sexually diverse groups, and throughout metropolitan, regional and rural areas. Carers' diversity is therefore evident in terms of cultural background, geographical region, age, socioeconomic status, their relationships with those they care for, and the range of conditions, illness or disabilities experienced by care recipients, to name just a few examples. As will be outlined in the following paragraphs, carers are likely to have different needs across their multiple roles and across the multiple dimensions of their own identities.

In what follows, various examples of carers' roles and identities will be outlined. This will provide insight into carers' multifaceted experiences and will lead to a discussion of what will be termed the 'carer persona' – illustrating the personal compromises and sacrifices that many carers make in fulfilling their vital social roles. These examples are not intended to provide an exhaustive list, but rather aim to highlight several of the possible roles and personas a carer may undertake.

Carer as woman or carer as man

As discussed by Ussher and colleagues, caring is not a gender-neutral experience, but is associated with a carers' expectations of being a woman or a man (Ussher et al. 911). Gendered stereotypes have been found to play a significant role in carers' reasons for taking on caring responsibilities, with the social pressure felt by women to assume caring roles contributing to their disproportionate overrepresentation within caring populations (Alpass et al. 789; del Río-Lozano et al. 1510). Male carers' experiences of caring can likewise be viewed through a lens of gender, often reflecting socially constructed ideas of the male role within a family – particularly an expectation to remain a figure of strength (Boström and Broberg 818). The traditional view of caring responsibilities being a female role within the family can also impact male carers' experiences. For example, caring may present alternative ways of expressing masculinity, or may assist in re-constructing gender identities (Eriksson et al. 244).

The gendered identities of carers hold significant ramifications for providing them with appropriate support, particularly in challenging social views that associate caring solely with women (Eriksson, Sandberg and Hellström 164). It is important to acknowledge that carers have specific needs and identities as either men or women, as well as the identities they develop in their caring roles. This is one example of why carers should not be viewed as a homogenous group. Rather than being solely conceptualised as a 'carer', or even ascribed more gendered titles (e.g., 'male carer', 'mother', etc.), there is merit in acknowledging that any individual carer is also a man or woman in his/her own right, and consequently experiences the same needs and pressures as any other individual within their broader gender population.

Carer as employee

While supporting loved ones is a major component of carers' lives, many also retain other significant commitments, such as employment. The degree of their involvement in each of these roles is influenced by the extent to which they identify as a carer or conversely, in terms of their occupation (Arksey and Glendinning 8). That is, do they consider themselves a carer who has a job, or an employee who has caring responsibilities? Employment can represent an integral part of carers' lives (George et al. 168), and it is therefore important to acknowledge their working identities alongside their needs as carers. Working identities are particularly important since caring for a loved one often inhibits workforce participation (Alpass et al. 790). Engaging in employment can have beneficial outcomes for carers in terms of their finances,

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social connectedness, health, wellbeing, and allowing time away from caring responsibilities. However, combining work and care can also increase stress and fatigue through managing conflicting time demands (Arksey 152). Carers have been found to endure significant stressors in order to continue working, demonstrating the importance they place on employment (George et al. 173). Workplace flexibility, involving a range of supportive practices, has been suggested as an essential approach to enable carers to balance work and care and thus remain in the workforce (Arksey and Glendinning 3; George et al. 173). Flexibility therefore demonstrates the practical benefits of respecting and supporting carers in both caring and employment roles. As well as their carer identity and the needs associated with that role, working carers have the same workplace identity as any other employee in that position would have. In addition, working carers develop a unique identity in balancing these two roles. Depending on the individual situation, balancing work and care can result in very specific individual support needs.

Carer as family member

The individual relationships between carers and their family members must also be considered. When support needs are aggregated to a family level, the individual concerns of carers and those they care for may be overlooked, as may relationship-specific issues (Ingleton 193). While the term 'carer' has been used as a label to describe their supportive role, research also highlights the importance of respecting different interpersonal relationships, and therefore acknowledging that caring comprises part, but not all, of the relationship dynamic (La Fontaine and Oyebode 1268). As outlined in the following paragraphs, carers' specific family relationship identities are worthy of individual consideration.

Carer as spouse/partner

Caring for a spouse or partner is widely reported as a natural extension of the existing relationship, that is, as an expression of love, commitment, and emotional connection (e.g., del Río-Lozano et al. 1510). Nevertheless, complexities within an intimate relationship and caring role must be negotiated, for example, by separating illness or disability from interpersonal aspects of the relationship (La Fontaine and Oyebode 1266; Lawn and McMahon 258). This is further emphasised by many spousal carers not identifying themselves as 'carers', but rather preferring to label themselves as 'partners', 'husbands', or 'wives'. Such a viewpoint focuses on the relationship above all else, with their partner seen as a person, wife, or husband first, and a care recipient second (Lawn and McMahon 258). Carers' needs within these relationships can be particularly impacted as care needs change over time and there is a consequent shift in the relationship. For example, carers of spouses with dementia may come to find that over time their partner is no longer able to fulfil the mutually supportive roles they once did, but become more reliant on daily caring activities (Savundranayagam 46). Under circumstances such as these, the relationship shifts from a mutual status to being characterised by increased dependence on one party. Subsequently, each person's role within the relationship also shifts. Regardless of the specific context, carers' identities as a spouse or partner exist beyond their role within the caring dyad.

Carer as parent

Upon receiving a diagnosis of a serious illness or disability for their children, carers' perceptions of their parental role can be significantly affected (Boström and Broberg 817). Caring for a child after such a diagnosis may be seen as a parent's duty and moral obligation (del Río-Lozano et al. 1510). This is reflected in responses to a state-wide survey of carers conducted by Carers NSW. When asked why they began their caring role, 36.7% of those caring for a son or daughter reported an emotional obligation, 50.4% indicated it was their family responsibility, and 56.5% reported they wanted to take on the caring role. In addition, approximately 20% of those caring for a son or daughter made a comment about their reasons for beginning their

caring role that highlighted their parental relationship, such as, "Because he's my son", "She's my daughter", and "Because I'm mum!" (Carers NSW 21). In order to behave in a manner consistent with the identity of a 'good parent', carers report undertaking extensive efforts to ensure their child experiences what they would consider to be a 'normal' childhood and also making substantial accommodations to family lifestyle as their child's needs dictate (Burton, Lethbridge and Phipps 1170; Seltzer et al. 281).

Carers' parental needs and desires may be significantly challenged in light of their child's disability, illness, mental illness, or other condition. While the individual child's autonomy, level of functionality, and other personal characteristics must be considered, carers' initial expectations of raising a child until adulthood are replaced with very different trajectories, as are expectations of how parent-child relationships may develop and function. Depending on their child's level of independence, a carer's parenting trajectory may also be significantly altered, with many continuing an active parenting role beyond typically expected timeframes. Several implications of these particularly long-term parenting responsibilities exist, not least of which relates to carers' concerns regarding their children's care when they are too old to adequately provide care themselves (Carers NSW 43). Parental identity can become a particularly complex issue amongst those caring for an adult child with a disability. These carers face balancing their child's right to independence and their parental responsibility to protect them from harm (Foley 298). The role identity of a parent can therefore be seen to uniquely exist within these caring situations.

Carer as son or daughter

For those caring for a parent, acting as both carer and son or daughter can result in role conflict. As with carers of adult children, carers of elderly parents can face the desire to maintain their parent's independence alongside a conflicting compulsion to protect them (Gill and Morgan 715). They are faced with the challenge of considering how to best support their parents at the present time and in the future, which includes facing issues of dependency and potential moving into a residential care facility (Gill and Morgan 716). These carers experience a shift in the relationship with their parent, from being a dependent child to taking on a supportive, or even parental, role. This process can be confronting for any carer supporting his/her parent, but is particularly likely to be challenging amongst young carers (i.e., those aged 25 years and under) (Abraham and Stein 609; Kavanaugh, Noh and Studer 21; Kieffer-Kristensen and Johansen 1565). Nevertheless, despite short-term challenges and burdens, evidence exists to suggest that there are long-term benefits of 'parentification' for young carers (Stein, Rotheram-Borus and Lester 330; Tompkins 120). Considering the role and relationship implications of the shift towards 'parentification', the needs of carers as sons or daughters of care recipients become apparent. As relationship dynamics shift from being the dependent party to being the source of support, these carers may lose the support, advice and wisdom of older generations. The interpersonal and intergenerational aspects of a child-parent relationship are likely to remain in situations of caring for a parent, further exemplifying the potential complexities that exist within certain caring relationships.

Carers as service providers

In many cases, carers take on a role akin to that of a service provider. The ability of family members to provide care is an inherent assumption in many service policies, as is the expectation that they will take on this caring role (Jowsey et al. 382; Ward-Griffin and McKeever 91). Carers may take on a myriad of roles reflective of a service provider, including, but not limited to: service coordination and management, advocacy, protection, monitoring symptoms, psychological support, health promotion, and ensuring treatment adherence (Cain, MacLean and Sellick 267; Safe, Joosten and Molineux 298).

With this extensive contribution in mind, the need to recognise carers' abilities and expertise has been identified (Boyd et al. 590). Furthermore, although this involvement can

potentially become burdensome (e.g., Safe, Joosten and Molineux 299), many carers report frustration when they are unable to be heavily involved in treatment plans for those they care for (Brobäck and Berterö 343). Carers are therefore likely to have specific concerns relating to the component of their role that pertains to service provision and treatment.

THE 'CARER PERSONA'

Despite the multitude of roles outlined above (and carers' specific needs within each context), a great deal of research has found that carers tend to minimise or neglect their own needs in order to focus on the needs of the person they care for (Carduff et al. A17; Hallé and Le Dorze 1777; Ussher and Sandoval 953). This 'carer persona' reflects the masking of their own needs in order to present a social identity focused on their caring role. Once the carer role has commenced, research suggests that it can dominate and overtake all of an individual's other roles and responsibilities, particularly the need to care for themselves (e.g., del Río-Lozano et al. 1516). Carers may feel that they cannot justify spending time on themselves if they perceive this as detracting from fulfilling their caring responsibilities (Safe, Joosten and Molineux 299). While Jungian theory suggests an inherent 'falsehood' surrounding the persona (i.e., what others and the self believe one is, but really is not), the 'carer persona' is often a genuinely selfless identity. As discussed previously, the 'falsehood' of the persona exists in relation to interacting with the social world in a manner that conforms to behavioural expectations of a given role. In other words, the individual's prime concern is with how they appear to others. In taking on the 'carer persona', however, carers legitimately ignore themselves and their own needs in potentially difficult or stressful circumstances, and often experience significant personal ramifications as a result (Ussher and Sandoval 954). For example, carers have been widely reported as experiencing particularly low levels of wellbeing in comparison to the wider community (e.g., Carers NSW 34; Cummins et al. 4). Despite this, many carers report that caring is an inherently positive experience, and often emphasise the positive aspects of caring for a loved one over any difficulties or burdens they face in their role (Carers NSW 26; McConnell et al. 39). This demonstrates the genuine nature of the 'carer persona' – rather than masking the 'true' self to present a more socially desirable face to the social world, the 'carer persona' masks carers' own needs through the sincerity of their primary concern for the wellbeing of those for whom they care.

The consuming nature of the caring role can result in carers feeling as though they have lost their wider self-identity, with their lives focusing on their caring role (Griffith and Hastings 411; Lawn and McMahon 260). This loss of wider identity may be considered a positive experience, with carers embracing their role and the significance of other roles paling in comparison (Griffith and Hastings 412). That is, the role of supporting and caring for a loved one is simultaneously more important and more personally fulfilling than addressing any of their own needs. Therefore, while the 'carer persona' may result in neglecting personal wellbeing, identifying as a carer in this way can also provide a sense of personal identity coherence by continually growing further into the 'carer persona'.

A common theme throughout literature is carers' minimising of their own support needs. This issue of support is complex. While carers readily acknowledge the need for services to support carers, a general reluctance to personally receive assistance is common (Cain, MacLean and Sellick 268; Eriksson, Sandberg and Hellström 163). Many carers admit they will need to receive support at some point in the future, but it is often a small minority who believe they have reached this point (Carers NSW 43). This is particularly the case when carers emphasise the support needs of those they care for. The tendency to downplay personal support needs is often a function of the 'carer persona' and interpreting caring experiences in relation to expectations of others (Eriksson, Sandberg and Hellström 164). Through this dedication, many carers demonstrate their social expectations to be capable of coping without much need for

support themselves (Ussher and Sandoval 954). In this way, the 'carer persona' can be seen to reflect the identity that carers believe they should portray to the social world.

DISCUSSION

The concept of the 'carer persona' as outlined above has ramifications in terms of recognising carers and their contribution to the wider community, and also in supporting them as they carry out their roles. As described by Jung, the persona represents a compromise between who a person truly is and the person they believe their social world expects them to be (Jung "Collected Works Vol. 6" 218). This paper has provided specific examples of some identities that carers are likely to hold, namely, female or male, employee, spouse/partner, parent, child, or service provider. While these identities represent certain dimensions of who carers are, research also reflects a persona they often present to the social world, which is characterised by the needs of those for whom they care. Just as Jung's persona is likened to a mask that hides the true self, the needs of care recipients can mask the needs of carers and their multiple identities.

The masking of carers' needs across their multiple identities reflects an important aspect of the Jungian persona – that it is predominantly formulated by society (Jung "Collected Works Vol. 7" 41). Social expectations often place carers in a position of focusing on the needs of those they care for, rather than their own. These expectations are particularly significant in discussing the 'carer persona', as many health and community services and related policies rely on informal carers and their willingness to maintain a caring role (Jowsey et al. 382; Ward-Griffin and McKeever 91). Carers' identities as they relate to being a 'service provider' (as described above) directly relate to this aspect of persona. As well as having personal needs related to a service provider identity, the 'carer persona' suggests that these needs are masked by those of the people for whom they care. Due to the reliance that many policies place on carers and the role they play, carers' interactions with service providers can lead to the construction of an identity that focuses on supporting care recipients and neglects their personal support needs – the essence of the 'carer persona'.

The concept of the 'carer persona' and its premise of carers' needs being masked can be understood in relation to the notion of falsehood that strongly permeates the Jungian concept of persona. However, this is not to suggest that carers are misleading or untrustworthy. Rather, the falsehood that exists within the 'carer persona' represents a false attitude that carers do not require care themselves. It must be noted that literature widely demonstrates many carers who exhibit resilience and effective coping strategies, and even flourish in their role with additional caring responsibilities (e.g., Broady, sect. 3, par. 1; Griffith et al. 243; McConnell, Savage and Breitkreuz 843). Nevertheless, many carers do require support or assistance in their role to some degree – a fact that the 'carer persona' is likely to mask.

The masking of carers' support needs reflects the notion of 'hidden' carers – those who do not identify as being a carer. Despite providing significant amounts of care and support to loved ones, many carers do not consider themselves 'carers' (Cass et al. 93; Moore and McArthur 565). This lack of identification often relates to the nature of caring relationships, a greater readiness to identify themselves in terms of that relationship, and societal norms related to caring such as those outlined in this paper (Smyth, Blaxland and Cass 146). Furthermore, many carers do not consider their caring responsibilities to be any different from any other 'typical' family member (Smyth, Blaxland and Cass 147). The minimising of one's own needs and responsibilities is indicative of the 'carer persona'. In such instances, the persona is used a defensive strategy. As a façade to the 'true' self, this persona is utilised to avoid confronting the reality of their caring situation, whether in terms of acknowledging the difference between their caring responsibilities and 'normal' family relationships, or accepting any special needs demonstrated by their loved ones. 'Hidden' carers is therefore a key example

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of the 'carer persona' in practice, and points towards the importance of this concept. Denying the label 'carer' represents a significant example of neglecting one's own needs in order to focus on the person in need of care. Those who do not identify with this label are typically less likely to access carer-directed support services (including government financial assistance), often due to not considering their caring responsibilities to be any more significant than typical family duties. By highlighting the nature of the 'carer persona' and the related neglect of personal needs in favour of focusing entirely on the needs of those for whom they care, increased efforts in identifying carers and their personal support needs are encouraged (whether or not they willingly identify themselves as such).

The concept of the 'carer persona' presented in this paper therefore has implications for carer related policy and service provision. In particular, the persona can be a useful tool for communicating and discussing the needs of carers at a population level. As discussed throughout this paper, carers have their own individual needs across different domains of their identity, aligning with the various roles they undertake throughout the course of daily life (e.g., woman or man, employee, spouse/partner, parent, son/daughter, service provider). Alongside these various aspects of their individual identities, carers will simultaneously have needs reflective of their caring roles. Importantly, the concept of the 'carer persona' suggests that carers are likely to downplay or completely neglect these needs in the interests of focussing solely on the needs of those for whom they care. Implications for service provision therefore exist around identifying carers and finding ways of effectively supporting them as they continue to care for loved ones. As discussed above, this is particularly important in the context of 'hidden' carers, who are not only likely to ignore their own needs, but also do not identify themselves as carers. The concept of the 'carer persona' as discussed in this paper highlights the responsibility of service providers in identifying, recognising, valuing and supporting carers in their roles. Since the 'carer persona' suggests that carers are unlikely to seek support for themselves, those providing services to care recipients are well-placed to not only identify carers, but to provide support or referral pathways to ensure their (neglected) needs can be more effectively met. Similarly, any carer-focused policy would benefit from an understanding of the 'carer persona' by ensuring that policies are framed and implemented in such a way as to recognise, value and support all carers, regardless of the extent to which they identify as a carer, or the extent to which they seek support for themselves.

The concept of the 'carer persona' is also useful in terms of communication, particularly in the context of service provision, as the 'carer persona' is likely to become the basis for carers' interpersonal interactions with health professionals and service providers. Conversations and interactions between carers and service providers are likely to be influenced by carers' tendency to minimise their own needs and focus on supporting those they care for. However, by recognising the compromise between carers' individual personal identities and their social world, greater insight into their support needs may be achieved. Regardless of whether or not they identify as carers, or the extent to which their caring responsibilities mask their own needs, carers are likely to possess multiple identities and accordingly have varying support needs. Service providers who aim to support carers and those they care for must acknowledge these identities and the specific needs associated with them. In doing so, carers will be recognised and respected for the individuals they are, beyond their caring roles. Such individual recognition and support is imperative, and must exist at all levels of policy and practice, if carers are expected to continue providing their valuable contributions within their communities.

WORKS CITED

- Abraham, Kristen M., and Catherine H. Stein. "When Mom Has a Mental Illness: Role Reversal and Psychosocial Adjustment among Emerging Adults." *Journal of Clinical Psychology* 69.6 (2013): 600-15. *Wiley Online Library.* Web. 14 Feb. 2013.
- Alpass, Fiona, et al. "The Influence of Ethnicity and Gender on Caregiver Health in Older New Zealanders." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 68.5 (2013): 783-93. *Oxford Journals.* Web. 22 Jul. 2013.
- Arksey, Hilary. "Combining Informal Care and Work: Supporting Carers in the Workplace." *Health and Social Care in the Community* 10.3 (2002): 151-61. *Wiley Online Library.* Web. 18 Mar. 2013.
- Arksey, Hilary, and Caroline Glendinning. "Combining Work and Care: Carers' Decision-Making in the Context of Competing Policy Pressures." *Social Policy & Administration* 42.1 (2008): 1-18. *Wiley Online Library*. Web. 18 Mar. 2013.
- Boström, Petra K., and Malin Broberg. "Openness and Avoidance a Longitudinal Study of Fathers of Children with Intellectual Disability." *Journal of Intellectual Disability Research* 58.9 (2014): 810-21. *Wiley Online Library.* Web. 19 Sept. 2013.
- Boyd, Kirsty J., et al. "Living with Advanced Heart Failure: A Prospective, Community Based Study of Patients and Their Carers." *European Journal of Heart Failure* 6.5 (2004): 585-91. *Wiley Online Library.* Web. 23 Apr. 2014.
- Broady, Timothy. "Resilience across the Continuum of Care." *M/C Journal* 16.5 (2013). Web. 21 Oct. 2013.
- Brobäck, Gunilla, and Carina Berterö. "How Next of Kin Experience Palliative Care of Relatives at Home." *European Journal of Cancer Care* 12.4 (2003): 339-46. *Wiley Online Library.* Web. 23 Apr. 2014.
- Burton, Peter, Lynn Lethbridge, and Shelley Phipps. "Children with Disabilities and Chronic Conditions and Longer-Term Parental Health." *The Journal of Socio-Economics* 37.3 (2008): 1168-86. *Science Direct.* Web. 18 Sept. 2013.
- Cain, Roy, Michael MacLean, and Scott Sellick. "Giving Support and Getting Help: Informal Caregivers' Experiences with Palliative Care Services." *Palliative & Supportive Care* 2.3 (2004): 265-72. *Cambridge Journals*. Web. 23 Apr. 2014.
- Carduff, Emma, et al. "Understanding the Barriers to Identifying Carers of People with Supportive and Palliative Care Needs in Primary Care." *BMJ Supportive & Palliative Care* 4.Suppl 1 (2014): A17. *BMJ.* Web. 27 Feb. 2014.
- Carers NSW. Carers NSW 2014 Carer Survey: Main Report. Sydney: Carers NSW, 2014.
- Cass, Bettina, et al. *Young Carers in Australia: Understanding the Advantages and Disadvantages of Their Care Giving.*: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2009.
- Cummins, Robert A., et al. *The Wellbeing of Australians Carer Health and Wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University, 2007.
- del Río-Lozano, María, et al. "Gender Identity in Informal Care: Impact on Health in Spanish Caregivers." *Qualitative Health Research* 23.11 (2013): 1506-20. *SAGE Journals.* Web. 8 Oct. 2013.
- Eriksson, Henrik, Jonas Sandberg, and Ingrid Hellström. "Experiences of Long-Term Home Care as an Informal Caregiver to a Spouse: Gendered Meanings in Everyday Life for Female Carers." *International Journal of Older People Nursing* 8.2 (2013): 159-65. *Wiley Online Library*. Web. 11 Apr. 2013.
- Eriksson, Henrik, et al. "His Helping Hands Adult Daughter's Perceptions' of Fathers with Caregiving Responsibility." *European Journal of Social Work* 16.2 (2013): 235-48. *Taylor & Francis Online.* Web. 27 May 2013.
- Foley, Simon. "Reluctant 'Jailors' Speak Out: Parents of Adults with Down Syndrome Living in the Parental Home on How They Negotiate the Tension between Empowering and

- Protecting Their Intellectually Disabled Sons and Daughters." *British Journal of Learning Disabilities* 41.4 (2013): 296-303. *Wiley Online Library.* Web. 11 Sept. 2012.
- George, Ajesh, et al. "Working and Caring for a Child with Chronic Illness: Challenges in Maintaining Employment." *Employee Responsibilities and Rights Journal* 20.3 (2008): 165-76. *Springer Link*. Web. 23 Jul. 2013.
- Gill, Elizabeth A., and Melanie Morgan. "Older Parents and Adult Daughters." *Research on Aging* 34.6 (2012): 714-37. *SAGE Journals.* Web. 4 Oct. 2012.
- Griffith, Gemma Maria, and Richard P. Hastings. "'He's Hard Work, but He's Worth It'. The Experience of Caregivers of Individuals with Intellectual Disabilities and Challenging Behaviour: A Meta-Synthesis of Qualitative Research." *Journal of Applied Research in Intellectual Disabilities* 27.5 (2014): 401-19. *Wiley Online Library*. Web. 19 Sept. 2013.
- Griffith, Gemma Maria, et al. ""We Are All There Silently Coping." the Hidden Experiences of Parents of Adults with Asperger Syndrome." *Journal of Intellectual and Developmental Disability* 37.3 (2012): 237-47. *Informa Healthcare.* Web. 31 Jan. 2014.
- Hallé, Marie Christine, and Guylaine Le Dorze. "Understanding Significant Others' Experience of Aphasia and Rehabilitation Following Stroke." *Disability and Rehabilitation* 36.21 (2014): 1774-82. *Informa Healthcare.* Web. 6 Jan. 2014.
- Hudson, Wayne C. "Persona and Defence Mechanisms." *Journal of Analytical Psychology* 23.1 (1978): 54-62. *Wiley Online Library.* Web. 11 Mar. 2014.
- Ingleton, Christine. "The Views of Patients and Carers on One Palliative Care Service." *International Journal of Palliative Nursing* 5.4 (1999): 187-95.
- Jowsey, Tanisha, et al. "Time to Care? Health of Informal Older Carers and Time Spent on Health Related Activities: An Australian Survey." *BMC Public Health* 13.1 (2013): 374. *BioMed Central.* Web. 8 Aug. 2013.
- Jung, Carl Gustav. *The Collected Works of C. G. Jung*. Vol. 7. 2nd ed. Princeton, New Jersey: Princeton University Press, 1966.
- ---. *The Collected Works of C. G. Jung*. Vol. 6. 2nd ed. Princeton, New Jersey: Princeton University Press, 1971.
- Kavanaugh, Melinda S., Hyunjin Noh, and Lynette Studer. ""It'd Be Nice If Someone Asked Me How I Was Doing. Like, 'Cause I Will Have an Answer": Exploring Support Needs of Young Carers of a Parent with Huntington's Disease." *Vulnerable Children and Youth Studies* 10.1 (2015): 12-25. *Taylor & Francis Online*. Web. 17 Nov. 2014.
- Kieffer-Kristensen, Rikke, and Karen Lise Gaardsvig Johansen. "Hidden Loss: A Qualitative Explorative Study of Children Living with a Parent with Acquired Brain Injury." *Brain Injury* 27.13-14 (2013): 1562-69. *Informa Healthcare*. Web. 14 Oct. 2013.
- La Fontaine, Jenny, and Jan R. Oyebode. "Family Relationships and Dementia: A Synthesis of Qualitative Research Including the Person with Dementia." *Ageing & Society* 34.7 (2014): 1243-72. *Cambridge Journals*. Web. 20 Mar. 2013.
- Lawn, Sharon, and Janne McMahon. "The Importance of Relationship in Understanding the Experiences of Spouse Mental Health Carers." *Qualitative Health Research* 24.2 (2014): 254-66. *SAGE Journals.* Web. 3 Feb. 2014.
- McConnell, David, Amber Savage, and Rhonda Breitkreuz. "Resilience in Families Raising Children with Disabilities and Behavior Problems." *Research in Developmental Disabilities* 35.4 (2014): 833-48. *Science Direct.* Web. 3 Feb. 2014.
- McConnell, David, et al. "Benefit-Finding or Finding Benefits? The Positive Impact of Having a Disabled Child." *Disability & Society* 30.1 (2015): 29-45. *Taylor & Francis Online.* Web. 17 Dec. 2014.
- Moore, Tim, and Morag McArthur. "We're All in It Together: Supporting Young Carers and Their Families in Australia." *Health and Social Care in the Community* 15.6 (2007): 561-68. *Wiley Online Library.* Web. 23 Apr. 2014.
- Safe, Anneleise, Annette Joosten, and Matthew Molineux. "The Experiences of Mothers of Children with Autism: Managing Multiple Roles." *Journal of Intellectual and Developmental Disability* 37.4 (2012): 294-302. *Informa Healthcare.* Web. 26 Nov. 2012.

- Savundranayagam, Marie Y. "Receiving While Giving: The Differential Roles of Receiving Help and Satisfaction with Help on Caregiver Rewards among Spouses and Adult-Children." *International Journal of Geriatric Psychiatry* 29.1 (2014): 41-48. *Wiley Online Library.* Web. 9 Dec. 2013.
- Seltzer, Marsha Mailick, et al. "Life Course Impacts of Parenting a Child with a Disability."

 American Journal on Mental Retardation 106.3 (2001): 265-86. American Association on Intellectual and Developmental Disabilities. Web. 23 Jul. 2013.
- Sharp, Daryl. *C. G. Jung Lexixon: A Primer of Terms of Concepts*. Toronto: Inner City Books, 1991. Smyth, Ciara, Megan Blaxland, and Bettina Cass. "'So That's How I Found out I Was a Young Carer and That I Actually Had Been a Carer Most of My Life'. Identifying and Supporting Hidden Young Carers." *Journal of Youth Studies* 14.2 (2011): 145-60. *Taylor & Francis Online*. Web. 15 Oct. 2012.
- Stein, Judith A., Mary Jane Rotheram-Borus, and Patricia Lester. "Impact of Parentification on Long-Term Outcomes among Children of Parents with Hiv/Aids." *Family Process* 46.3 (2007): 317-33. *Wiley Online Library.* Web. 7 Aug. 2013.
- Tompkins, Tanya L. "Parentification and Maternal Hiv Infection: Beneficial Role or Pathological Burden?" *Journal of Child and Family Studies* 16.1 (2007): 108-18. *Springer Link.* Web. 7 Aug. 2013.
- Ussher, Jane Maria, et al. "The Gendered Construction and Experience of Difficulties and Rewards in Cancer Care." *Qualitative Health Research* 23.7 (2013): 900-15. *Taylor & Francis Online.* Web. 1 Oct. 2013.
- Ussher, Jane Maria, and Mirjana Sandoval. "Gender Differences in the Construction and Experience of Cancer Care: The Consequences of the Gendered Positioning of Carers." *Psychology & Health* 23.8 (2008): 945-63. *SAGE Journals.* Web. 1 Oct. 2013.
- Ward-Griffin, Catherine, and Patricia McKeever. "Relationships between Nurses and Family Caregivers: Partners in Care?" *Advances in Nursing Science* 22.3 (2000): 89-103.

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