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INTRODUCTION

Media reports tell of the increasing global burden of an ageing population, both financially and in care provision (Conway, 2010). In the U.K. the debate on euthanasia and assisted suicide has become more prominent with some disabled, elderly and physically ill people making trips to the Dignitas clinic in Switzerland to end their lives. Baroness Warnock stated that frail elderly people should think about euthanasia so as not to financially burden their families (Templeton, 2004). This could suggest that to be dependent and in need of care is to be a burden. Those requiring help often say ‘I don’t want to be a burden’ and when receiving help some experience themselves as a burden (Angus & Reeve, 2006; Charmaz, 1991; Chochinov et al., 2007). This is of interest as most people will require help at some point in their lives and so potentially could feel this way. Groups such as the elderly, the disabled and the physically or mentally ill who may need help in order to survive could be especially vulnerable to experiencing this sense of being a burden to others. This review will ask what psychology has to say about feeling like a burden. It will examine the research available and explore the psychological and social consequences for individuals who feel this way. Psychology has been criticised in the past for individualising distress and for not exploring wider political and societal reasons for psychological problems (Hare-Mustin & Marecek, 1997); therefore, the review will also consider how a sense of burden is socially constructed and suggest ways of addressing the problem alongside areas for future study.

Feeling like a burden has increasingly been researched by those interested in end-of-life issues and terminal or chronic illnesses (Chochinov et al., 2002; Chochinov et al., 2007; Cousineau, McDowell, Hotz & Hebert, 2003; McPherson, Wilson, Lobchuk, & Brajtman, 2007; McPherson, Wilson & Murray, 2007; Wilson, Curran, & McPherson, 2005). This body of research focuses on participants in Western societies and is both qualitative and quantitative. The phenomenon, generally termed ‘self-perceived burden’ has been defined as: “empathic concern engendered from the impact on others of one’s illness and care needs, resulting in guilt, distress, feelings of
responsibility and diminished sense of self.” (McPherson et al., 2007b, p. 425). This proposes a psychological construct not linked to dependence. Although a previous definition proposed by Cousineau et al. (2003) was linked to feelings of dependence, McPherson et al. (2007b) demonstrated that people could feel they were a burden even when they were not dependent on others. As dependence is a subjective concept (Verbrugge, Mehta & Wagenfeld-Heintz, 2006), although researchers may perceive participants were not dependent (using functional ability measures) this does not mean that they did not ‘feel’ dependent. Ideals of independence feature strongly in the literature as associated with feeling like a burden suggesting that ‘perceptions’ of dependence could be included in the definition. This body of research has explored the correlates of the phenomenon quantitatively and has elaborated the personal and social experience for individuals qualitatively. A second body of quantitative research has considered ‘perceived burdensomeness’ – a predictor of suicidal behaviour defined as: ‘the view that one’s existence burdens family, friends, and/or society’ (Joiner et al, 2009, p. 634.). This work has been conducted with ethnically diverse populations and with those suffering from mental rather than physical illness, although still within Western societies. At first glance self-perceived burden and perceived burdensomeness would appear to be the same however, as perceived burdensomeness is not linked to physical illness or care needs this is considered to need further exploration.

Those conducting quantitative research have attempted to measure feelings of being a burden. Cousineau et al. (2003) devised a scale to measure self-perceived burden in patients with chronic illnesses which Simmons (2007) validated with cancer patients. Although the scale showed promise during validation the conceptual model used had to be simplified. As part of this process items related to indebtedness were removed. This appears counterintuitive as an inability to reciprocate has been proposed as contributing to feeling like a burden (Lewinter, 2003). As well as not showing whether these instruments are of use with other cultures or other groups who are not physically ill, such as the elderly, disabled or mentally ill, it seems that measurement may involve a simplification which does not reflect the multidimensional nature of feeling burdensome. Joiner et al. (2009) when researching perceived burdensomeness, in relation to suicidal behaviour, also experienced problems. They used a ‘mattering’ scale and items from a suicide probability scale to measure the concept. They
acknowledged that although perceptions of ‘mattering to others’ were similar to perceived burdensomeness this was ambiguous. The authors thought that using the suicide scale measured the concept more clearly using four items related to feelings of incompetence, ineffectiveness and being a burden to others. Exploring how similar the two concepts of burden are may enable these tools to be refined. However, it appears that measuring this complex phenomenon is problematic at present.

Critically almost all the studies have taken place focusing on Western societies and most have not taken into account ethnicity or different cultural contexts. Research into topics aligned to ageing and disability often refer to feelings of burden so these are discussed where relevant. The above bodies of research show strong social influences on the phenomenon. Therefore, the review includes literature taking a constructionist stance and some of the cross-cultural research available.

**Psychological consequences of feeling like a burden**

Wilson, et al.,(2005) showed that a sense of burden, for terminally ill patients, did not occur on its own but correlated with many other concerns such as loss of dignity, loss of control, hopelessness, loss of quality of life, depression and a reduced wish to live. Physical symptoms were not the most important factors; the correlations with psychological distress were more salient suggesting that feeling like a burden is linked to psychological experience more strongly than bodily experience. Chochinov et al. (2007) also quantitatively assessed terminally ill patients’ sense of burden and its correlates with similar results. Sixty percent of their participants experienced distress attributed to feeling a burden to others. The most significant correlations were to hopelessness, depression and outlook. They found no association between degree of actual physical dependence and sense of burden and suggested psychological and existential factors influence the perception. That some people could be relatively able physically and still feel a burden and, contrarily, some who were very physically dependent not feel a burden would appear to indicate that there is a complex relationship between dependence and self-perceived burden.

As depression, hopelessness and a reduced quality of life link to suicidal ideation (Joiner, 2005) it is not surprising that feeling like a burden is associated with wanting
to die. Research shows that perceiving oneself as a burden to others can be given as a reason for wanting, or considering euthanasia in patients who are terminally ill (Chapple, Ziebland, McPherson, & Herxheimer, 2006; Wilson et al., 2007). In a study looking at vulnerability factors, in cancer patients who had committed suicide, fear of being a burden was one of the most relevant (Filiberti et al., 2001). It is also cited as a contributing factor in patients wishing to stop renal dialysis; which causes certain death (Ashby et al., 2005). Emanuel, Fairclough, Daniels and Clarridge (1996) used vignettes to examine the attitudes of oncologists, oncology patients and the general public to euthanasia and physician assisted suicide. One vignette described a pain free, terminally ill, cancer sufferer who felt they were becoming a burden to their family and requesting to end their life. Over 35% of the patients and members of the general public questioned thought the request should be granted. This demonstrates that a considerable number of people think that to feel like a burden is an adequate reason to hasten death. This attitude is echoed most recently by the wife of cricketer Chris Broad, who had motor neurone disease. She committed suicide aged 60 and the notes she left stated she did not want to become a burden (Brown, 2010).

Feeling like a burden has negative consequences not just for the physically ill. A link to suicide has been found within groups including psychotherapy outpatients, undergraduates and those who have attempted or completed suicide (Riberio & Joiner, 2009). Orden, Lynam, Hollar and Joiner (2006) found that perceived burdensomeness predicted suicide behaviour above and beyond hopelessness. This supports Joiner’s (2005) interpersonal-psychological theory of suicidal behaviour which proposes feeling like a burden to loved ones as a factor predicting suicide. The perception of burden is proposed to arise from a mistaken idea that the self is useless and hence the person can offer nothing to others and thus is a burden. The theory suggests that a sense of not belonging, alongside feeling like a burden, is a particularly dangerous combination. Riberio and Joiner (2009) suggest these two concepts are difficult to separate as one may induce the other and vice versa. The association of a sense of alienation with feeling like a burden points to a socially derived aspect of the perception. Ruckenbauer, Yazdani and Ravaglia (2007) claim that elderly people feeling they are a ‘burden’ to society are contributing to the increased suicide rate in this age group and, more worryingly, that it is being seen as a rational decision. It
appears, then, that feeling like a burden is linked to suicidal ideation for many groups within our society.

Charmaz’s (1983) qualitative work with those experiencing chronic illnesses is one of the first to show the lived experience of feeling like a burden. She used a symbolic interactionist analysis which presumes the self to be produced from social interaction in a continuous process. Her participants experienced themselves as burdening others. Some were concerned with psychological and financial burdens but most felt the physical care they needed was burdensome. Charmaz felt that this sense of burden emerged as a result of a loss of self through discrediting. This is a process where either through interaction or by not meeting their own expectations, the ill person’s self is discounted, demeaned or devalued. This discrediting can lead to the individual seeing themselves as useless, a failure and hence a burden to others. Charmaz thought for these people burden was linked to physical dependence unlike the findings of Chochinov et al. (2007) and McPherson et al. (2007b). What to be a burden actually meant to individuals, however, was subjective and emerged through interaction with others and in comparison to the expectations of the ill person. So participants were shown to have differing ideas about how they were a burden: for some needing meals cooked for them was enough for them to feel a burden; for others being physically immobile was the cause. The sense of being a burden led to feelings of uselessness both to others and the self, which increased psychological suffering.

In an extensive qualitative study into the experience of living with chronic illness Charmaz (1991) found that some of her participants had a terror of dependence; and that being dependent brought on feelings of guilt associated with perceiving themselves as a burden. For some the thought of dependence in the future was so dreadful they could no longer enjoy the present and were caught in a downward spiral of negative emotions. That the mere thought of dependence was enough to distress some implies that independence was highly prized, conferring a positive identity. More recently, Galvin (2005) used grounded theory to analyse data from disabled individuals and found that a theme of losing independence potentially had devastating effects on sense of identity. Some felt shamed, degraded and demoralised through their experiences of needing care from others, suggesting that independence remains a sought after state. Charmaz (1991) did find that some participants were able to
transcend their illness and retain a positive identity. This required a separation from society’s symbols of what it is to be a successful person. Independence, productivity and self-reliance needed to be abandoned as ideals and a redefinition of a ‘good life’ was needed.

More recently, McPherson et al. (2007b) also showed how self-perceived burden affects the self. They used interpretative phenomenological analysis to look at 15 terminally ill patients’ experience of feeling like a burden. Participants expressed concern for others around the physical, social and emotional burdens they perceived they were or might be in the future. Feeling like a burden to others aroused negative emotions such as guilt and frustration. The sense of burden was linked to dependence; the authors found that adjusting from a perceived sense of independence to a perceived sense of dependence led to feelings of uselessness and hence reduced self-worth. This had implications for participants’ sense of self because requiring help changed their self-concepts, which was difficult for participants to accept. This research also linked feeling like a burden to social roles as participants described a sense of failure when unable to carry out important social roles such as parenting.

Other researchers have also found that an inability to fulfil social roles is associated with feeling like a burden. Brenner et al. (2008) found that failure to fulfil social roles caused returning veterans to feel they were a burden to their families and this was linked to a loss of sense of self. Participants used minimising and concealing symptoms as a way of lessening the perceived burden on others. Ch’Ng, French and Mclean, (2008) found that for new stroke sufferers loss of social roles and reliance on others (suggesting a sense of burden) was linked to depression and even suicidal ideation. Finally, feeling like a burden is associated with shame. Smith and Osborn (2006) found an inability to maintain social roles caused individuals to feel they were a burden; which the authors suggest confirms a socially constructed facet of this illness. Individuals with chronic back pain described the shame felt about their condition as worse than the pain itself. This arose from the threat to identity caused by the inability to fulfil what they perceived as their valued roles and the fear of social judgement about this.
In research using a mixed-methods approach, the self-perceived burden scale was used by McPherson et al. (2007a) to assess the extent that self-perceived burden relates to a ‘social reality’ or is a mental construct. They used the measure along with a single-item interview, which gave a rating to sense of burden and compared this to carer’s assessments of the burden felt and measures of performance status. They found the correlations between caregivers’ rating of burden and self-perceived burden to be weak. Although there was a correlation between functional performance and caregiver’s sense of burden, this, too, was not strong. This reflects the paradox that individuals can be physically able and still perceive themselves as a burden and vice versa. Therefore, the ‘reality’ of feeling a burden is located somewhere other than in physical dependence, with the degree of burden felt being subjective. Additionally, the researchers found that caregivers were not very accurate in recognising when patients felt they had become a burden. This may indicate that people did not wish to show that they felt a burden or that it was difficult to recognise; either explanation points to potential difficulties in tackling the phenomenon. A later study with stroke patients and their carers’, however, showed caregivers as quite accurate in assessing self-perceived burden in care-receivers (McPherson, Wilson, Chyurlia, & Leclerc, 2010). As many variables such as extent of physical disability, relationship between caregiver and care-receiver and cultural environment could influence these judgements, further investigation to examine why these differences occurred is needed.

To feel like a burden emerges as a distressing experience, altering perceptions of self, relationships and quality of life. It is shown to increase suffering and be a negative experience associated with feelings of guilt and failure emerging from social interaction with social roles and a negative perception of dependence implicated. Personal expectations also play a part but these in turn are influenced by societal expectations. For the most part it had a negative effect on sense of identity, which suggests that cultural messages about preferred identities may play a role in the creation of the phenomenon. This research was all carried out within the West so only sheds light on a Western, capitalist society and its concept of what it is to burden others. Cross-cultural work, therefore, is also needed. Despite this limitation the work reported does give an insight into the complexity of the experience of feeling like a
burden and its far-reaching effects with decisions taken when feeling like a burden likely to be very different from those taken when not.

**Social implications of feeling like a burden**

Feeling like a burden influences and is influenced by social interactions. Charmaz (1983) found for her chronically ill participants interactions with others were subsequently changed as people became inward looking and were sensitive to any possible further discreditations of the self. Negative social identities associated with dependence were feared and action was taken to avoid them where possible. Men with chronic illnesses found asking for help demeaning; this combined with assumptions about masculinity based on autonomy and personal power made it difficult for them to find positive new identities or hold onto valued old ones (Charmaz, 1994). Therefore, cultural assumptions about gender influence the perception of feeling burdensome. Galvin’s (2005) disabled participants also chose to endure hardships and struggle to do things by themselves rather than ask for help, leading to increased personal suffering. These findings have been echoed by qualitative research exploring how adults with cerebral palsy experience their bodies (Sandstrom, 2007). The participants described struggling to appear ‘normal’ and how needing help made them feel like a burden. Hughes, Closs and Clark (2009) reviewed qualitative research into the experiences of the elderly with cancer and found that some individuals worked at lessening their sense of being a burden. They achieved this by reducing how much they spoke about their cancer, by planning funerals and offering spiritual support to family and friends. Hughes, Closs and Clark, (2009) proposed these efforts to lessen a sense of burden as a way of maintaining relationship rules of reciprocity so that support flowed both ways. Chochinov et al. (2007) also suggested that reciprocity plays a part in feeling like a burden. The authors suggest that the terminally ill may feel a burden as they perceive they have nothing to offer in interpersonal relationships. This is due to increasing care needs where they perceive they are taking but not giving and feelings of worthlessness arising from depression.

It is not just the presence of illness or disability which causes the perception; judgements about what it is to be ‘worthy’ are implicated which in turn are influenced by society. Lewinter (2003) also stressed the role of reciprocity in alleviating a sense
of burden. In her qualitative study of elderly Danish residents she showed that gift-giving to families and hospitality to formal carers was used to help alleviate a sense of burden. She stressed that as a care-receiver a ‘burden of gratitude’ could be amassed if some kind of reciprocity was not available, a finding echoed by Galvin (2005). The Danish welfare system was proposed by Lewinter as helping reduce this burden because it was equally available to all as recognition of their contribution to society. Thus, the elderly did not have to prove they were worthy of help, this was theirs by right. Calasanti and Slevin (2001) also suggested that fear of being a burden could be reduced for older people if care was offered to all elderly people rather than just dependent elderly. Galvin (2005) found that disabled individuals who had been able to adjust to needing support were almost all able to access formal care arrangements; those who had to rely on informal care through friends and family experienced frustration and shame about their need for help. This suggests that welfare and support structures may have a part to play in fostering feelings of burden.

Most of the research echoes that to feel a burden is a distressing experience. One study found a positive aspect of the phenomenon. Johnson, Sulmasy and Nolan (2007) used qualitative description and content analysis to examine three patients’ experience of being a burden. Participants gained satisfaction from the use of strategies to reduce the burden on their caregivers. The participants planned to enter care facilities in order to reduce the burden on their families; despite admitting they received a high level of emotional and social support from them. Thus, reducing a sense of burden may require actions that are not necessarily in the individual’s best interests. Feeling like a burden is a deeply undesirable state if it warrants such action. The findings for this study almost exclusively report on positive effects of managing the sense of burden. Negative experience does not appear in the themes, which is at odds with other research. Interviews were based on questions about activities and roles that patients could no longer carry out independently, so there was a presumption that feeling like a burden is based on physical dependence; and that independence and dependence were ‘real’ measurable states. These ontological assumptions may hide the extent of burden felt. Positive coping methods for helping reduce a sense of burden are important. However, if lessening the perception requires increasing personal suffering in those who are already ill, alternative strategies need to be found.
Research has shown what may contribute to a sense of burden and how it is experienced. It has also suggested that psychological interventions may help to alleviate it; exploring emotional reciprocity and past support given to others is one suggestion (McPherson et al., 2010). Whether self-perceived burden is a reality or a mental construct may depend on your epistemological stance but it is important to ask why some perceive care needs as burdensome in the first place. The feelings that arise from this perception appear to be negative and have implications for an individual’s quality of life so need to be addressed whether they arise from a ‘reality’ or not. Whilst, feeling like a burden has social implications for individuals, the links to ideology and welfare structures point to a constructed phenomenon.

**Burden as a Social Construction**

This literature extends some of the ideas discussed above, showing how cultural and societal ideals inform and shape the experience of illness and ageing and hence the sense of burden. Street and Kissane (2001) used discourse analysis to show discourses of the body that emerged from those who requested euthanasia. They found that fear of being a burden was given as a reason for desiring euthanasia and was linked to a discourse of a dependent and shameful body. Childlike dependence was contrasted with an independent rational decision for euthanasia. From this stance, becoming dependent on others positioned people as lacking in autonomy and infantilised thus a request for death reclaimed autonomy. This reflects a Western imperative to regulate the body as part of regulating the self; ideal bodies are self-contained and autonomous (Lupton, 2000). So, bodies that are dependent and ‘leaky’ (through incontinence, wounds, etc.) are positioned as shameful and causing burden. It appears that the effects of inhabiting a sick or dying body, within a Western society, can induce a sense of burden and shame.

Clarke, Griffin & the PACC research team (2008) studied older adults with five or more chronic conditions and showed that they experienced their bodies failing not just physically but socially. Participants linked loss of independence to being a nuisance and worthlessness, which implied a sense of burden. The experience of social failure suggests that ideology influences the experience of loss of independence and hence the sense of burden. The authors found that ideals of successful ageing and health,
both of which promote independence and self-care, were associated with this social failure. Calasanti (2007) showed how the ideal of successful and healthy ageing created a message that an inability to curb the ageing process and maintain health was a personal failure reducing individual worth. Hence, to feel a burden can emerge from not meeting societal expectations of independence. Angus and Reeve (2006) proposed that to age well means to remain independent; the responsibility, then, lies with the individual to take up healthy practices and to not burden the state. This is due to an economic ideal of productive individuals; and although both young and old are positioned as dependent the young are seen as having future potential and the older population are not. This can marginalise anyone who does not age well and masks factors such as social inequality which cause illness as well as age. Newer initiatives designed to help combat ageism, such as ‘healthy ageing’, continue to support the stereotypes as long as they are based on individual responsibility. However, Townsend, Wyke and Hunt (2006) found the obligation to maintain independence in younger people with multiple chronic illnesses. Participants in their fifties struggled to maintain favoured social roles such as ‘worker’, often to the detriment of their own health. The authors described this work as ‘moral’, suggesting that participants felt obliged to manage their physical symptoms due to cultural ideals of what it is to be an ‘acceptable person’. Therefore, an ideal of independence appears intrinsically linked to a sense of burden.

Williams (1993), using narrative analysis to explore the experiences of one woman with arthritis, implicates ideals of independence. Depending on an object for help was described as preferable to depending on human help. To be seen as independent was important morally and so his participant was keen not to be burdensome to family or state. He suggested that individualism and ideals of independence tend to overlook how much each of us is reliant on the resources we can access and build up over a lifetime. These, in turn, depend on social structures which are not necessarily equitable, so wealth can influence how burdensome an individual may feel. Independence was linked to a positive self-concept and loss of this was argued to be psychologically traumatic. Society’s influence was present in an individual feeling like a burden, as a moral imperative was attached to independence of body and an ability to fulfil social roles. If to be independent, therefore not burdensome, is promoted as a virtue, having a chronic disease disadvantages people not just
physically but socially too. Espvall and Dellgran (2010) also implicate wealth as it influences the amount of social support available. They found that in times of economic hardship, when the state may cut back on formal support available, those who have the least financial resources find it the most difficult to access informal financial support due to reciprocity ‘rules’ in interpersonal relationships. This has implications for the role of ‘reciprocity’ in helping relieve a sense of burden for it appears that ability to reciprocate is reduced when financial resources are limited. Thus, those who are wealthier may have more opportunities to reciprocate as long as money or ‘gift-giving’ is the currency used. Even if reciprocity is in the form of psychological support, this may still not be an equitable system as those with mental health problems or learning disabilities may not be able to offer this. Therefore, using ideas of reciprocity to counter self-perceived burden needs to be considered very carefully.

Theorists who propose that the elderly are constructed as dependent and a burden echo this idea. Townsend (1981), almost thirty years ago, argued that dependence in the elderly is created by social policy. He suggested that retirement and the ways the elderly are cared for position them as dependent, arguing that this has come about because of the demands of Western economic realities. Our social institutions, he suggested, act as regulators by confirming the inequality of those who do not conform to present social values such as self-help, independence and willingness to work. The elderly are denied employment and are positioned as passive, grateful recipients of care and hence dependence is socially created. So it follows that any sense of burden that is experienced as a result of this dependence is socially created. Phillipson (1998) also argued that the elderly are defined as a burden and a cost to society. Productivity is defined in a narrow way ignoring voluntary work, family care and self-care that the elderly may engage in thus they are positioned as a burden. Research appears to support this theory. Walker and Walker (1998) studied a group of older people with learning disabilities and found that as they moved service providers, because of their age, they were immediately disadvantaged. The focus of the service changed from fostering independence to supporting dependence. This led them to argue that dependence is socially constructed in the elderly, a stereotype that is especially resistant to change.
Rozario and Derienzis, (2009) studied how older people constructed their age identities through their talk. Their participants distanced themselves from dependence and lack of autonomy, through their narratives, as a way of presenting themselves as ‘not old’. Unfortunately this position that being independent makes one ‘not old’, which is emphasising the difference between the dependent old person and the independent ‘not old’ person, maintains the existing stereotype. The link between ageing and burden is thus maintained. Gergen (2008) suggested that the appropriate enactment of age in a Western society can involve presenting oneself as dependent. However, this is not just a Western phenomenon. Vera-Sanso (2006) showed how factors of economics and social class influenced dependence and so the definition of old age differed in rural and urban India. So, ageing is a socially constructed artefact (Rozario & Derienzis, 2009) and is associated with negative stereotypes such as being dependent and hence a burden (Gergen, 2008). This puts older people in an unenviable position; they are destined to be seen as a burden. Mental illness has also been linked to constructed dependence. Williams and Collins (2002) showed that discourse helped to construct schizophrenics as dependent. Whether this generated a feeling of burden was not explored.

Galvin (2005) suggested that the needs of the disabled are framed by society in terms of burden consequently they feel they have to constantly express gratitude towards helpers. Additionally, she suggested that the ideology of individualism that dominates Western society implies an obligation to take care of oneself, and anyone who fails in this is morally inferior. Overcoming this shame needs a redefinition of independence as something other than being able to care for oneself. Her participants used the concept of an independent state of mind, linking it to an ability to make choices, and disputed that anyone was truly independent. This points the way to how identity can be constructed in a positive way even in the face of negative societal messages. Some also resisted the individualisation of disability. They placed it as a public problem hence it was no longer their responsibility to cope alone and they did not need to see dependence as a diminishing their identity.

Davies and Watson (2002) proposed that the negative depiction of the disabled starts in childhood. Disabled children are presented as a burden and drain on society and subsequent help is aimed at the individual with little recognition of society’s role in
making problems for this group. The narratives of parents with disabled children (Fisher, 2007) showed resistance to the ideal of independence. These parents rejected the concept that to be an independent, self-sufficient person was the only way to lead a ‘good life’; suggesting different ways of being. These studies, although not directly investigating sense of burden, point to how a discourse of being a burden can be resisted. It was rejected by both those who may have it forced upon them (the disabled) and those who may be expected to feel burdened (parents of the disabled).

Some authors suggest that interdependence rather than independence is more reflective of the human condition (Kittay, Jennings & Wasunna, 2005; Fine & Glendinning, 2005 & Robertson, 2001). Kroger (2009) commented that research on care and research on disability traditionally had different foci but more recently were sharing common ideas. He suggested that interdependence, as proposed by those researching care, and independence meaning autonomy rather than self-sufficiency, as defined by disability researchers, bring the two fields closer together. This poses interesting questions about feeling like a burden, for ideology appears to be implicated in how ‘burden’ is perceived. If interdependence rather than independence was the over-riding model of ‘a good life’ would this sense of being a burden be lessened? Additionally, is there something about the traditional oppositional model of carer versus care-receiver that produces this sense of being a burden for one and being burdened for the other?

Cross Cultural Research

Research with other cultures has shown that to feel a burden is not restricted to the West; however, it also shows that what is meant by the term burden can differ culturally. Perceiving that one is a burden to family members during terminal illness was found to cause existential distress to Jewish and Middle Eastern cancer sufferers (Blinderman & Cherney, 2005). This distress was discussed in connection to a perceived lack of autonomy and dignity, and being a burden was a constituent part of this. Singer and Bowman (2001) examined the attitudes of Chinese elders (living in Canada) to end of life decisions and found that they did not want to burden family, state or healthcare services. They linked this desire not to burden to religious and philosophical attitudes that emphasised community and interdependence, thus the
resources of the community needed to be considered. Choosing to die would hence be perceived as a compassionate act towards community and family. These studies show that it is not just society’s with an ideology of individualism that can generate a sense of burden; however, research has highlighted differences in how being a burden is perceived across cultures.

Cahill, Lewis, Barg and Bogner (2009) found that black and white, elderly adults applied different meanings to being burdensome. Black older adults were less likely to express that they felt like a burden. When they did feel like a burden this was associated with losing their independence and with not being able to contribute to social networks. White older adults associated being a burden with inconveniencing their families and causing extra work. So although both groups did not want to burden their families there were subtle differences in what ‘to burden’ meant. Ball, Perkins, Hollingsworth, Whittington and King (2009), however, whilst using grounded theory to examine the influences of race and class on decisions to move into assisted living facilities, found that both black and white elderly people cited not wanting to burden their families as a reason for moving. Feeling a burden was linked to a loss of independence and autonomy for both groups. Candib (2002) found cultural differences in how independence and autonomy are perceived within America. Using case examples she showed how some Native-American, Vietnamese-American and African-American families were ‘family autonomous’ rather than ‘individually autonomous’. This meant that families made decisions together about an individual’s care rather than the family member on their own being responsible for the decision. This affected their perception of where responsibility for decisions about an individual’s healthcare lay. For some African-American families community presence was important and life was valued whatever the ‘burden’. Whether the individuals themselves felt a burden was not explored but the research points to different cultural attitudes towards burden. If ‘being a burden’ is linked to autonomy and independence then cross-cultural difference in these constructs may indicate differences in what it is to ‘be a burden’.

In a study looking at the differences between American and Singaporean elders, 50% of Singaporean elders and 45% of the American elders expressed negative feelings about accepting help. They cited feeling a burden as a reason for this (Verbrugge,
Mehta & Wagenfeld-Heintz., 2006). Singapore is depicted as a more interdependent society than America with a tradition of elders living with their families. The elders interviewed all expected care from their families, but this did not stop them feeling a burden sometimes. How this group conceptualised ‘burden’ was not explored and it would be interesting to see how ‘burden’ is experienced in this interdependent society. Additionally, the researchers found that independence and dependence were subjective phenomena and differed widely between the two groups. None of the Singaporeans claimed total independence as opposed to 20% of the Americans. Murray, Grant, Grant and Kendal (2003) showed what it is to be a burden in a non-Western society. They interviewed terminally ill people in Kenya and Scotland and found, although both did not want to burden their loved ones, Kenyans were concerned with financial and physical burden and the Scots were concerned with the emotional burden. This may reflect the economic differences between the two countries showing how ‘feeling like a burden’ is influenced by the wider environment. These studies show that to feel a burden is a subjective state which can be influenced by financial, community and family concerns. It is also linked to a sense of diminished autonomy and dependence, which are not static concepts but differ culturally so, although it seems that many may feel like a burden, what is meant by this can differ depending on cultural environment.

CONCLUSION

The literature reviewed here shows that feeling like a burden is a complex construct. It occurs in the chronically and terminally ill, the disabled, the elderly and the suicidal, all of whom could be described as vulnerable groups within society. It is a psychological construct not necessarily linked to actual dependence but associated with many negative states of mind. Through qualitative research the negative effects on an individual’s self identity emerges, linked to social ideals of autonomy and independence. Additionally, maintaining social roles is shown to be important as a way of feeling that one is not a burden. The evidence cited demonstrates differences in how being a burden is experienced and constructed, not just individually but also culturally. The influence of society is illustrated throughout suggesting that feeling like a burden emerges from social interaction. So, this sense of burden is not a static entity, it evolves and changes through time and place. Discourses surrounding age,
disability, illness and independence may contribute towards feeling like a burden. Interdependence and autonomy were suggested as ways to start re-thinking dependence, which seems inextricably linked to the phenomenon. Thus to feel a burden is an inherently subjective experience influenced by a multitude of factors including culture, family, society and financial situation.

As previously stated, it is part of the human condition to need care at some point in our lives, but it appears as a society we can perceive this natural occurrence as burdensome to others. As this is a source of distress to many it would seem that exposing these assumptions and examining and debating them in public is one way to start to address this problem. Further research is needed to find out how this sense of burden is constructed and how to alleviate it when it occurs. If, as suggested above, this is a socially constructed phenomenon then research into how ‘burden’ is constructed and experienced within all aspects of society is needed. A critical examination of how ‘patients’ or ‘clients’ are constructed within medical and psychological professions, as well as by carers and the general public, is needed to ensure discriminatory discourse is not being perpetuated. The present economic climate and talks of the need for swinging cuts within healthcare and the welfare state may result in more people feeling like they are a burden: an exploration of the discourses surrounding care-receivers within this climate is needed urgently. Additionally, as financial status and welfare structures are implicated as playing a part in the construction, further research looking at how a perception of burden is influenced by these is needed. Contrarily, the experience of those who need care but are able to escape this phenomenon would be of interest; to uncover potential alternative discourses.

Chochinov et al. (2007) suggest that psychological interventions targeting meaning, purpose and depression could be helpful, so research into the specific ways that therapy can address this are needed. Refining and validating the self-perceived burden scale for use with groups such as the elderly could be useful. Exploring the overlap between ‘self-perceived burden’ and perceived burdensomeness may also help in refining the measurement of this phenomenon. More quantitative and qualitative research with groups other than the physically ill is needed to see how far reaching this phenomenon is. The associated contributing factors and correlations also need to
be examined to see if the perception differs within and between groups. In all these areas of future research cross-cultural studies are needed to see how universal these perceptions are.

Dependence and sense of burden have been shown to be socially constructed by the above research. These discourses, however distasteful we find them, play a part in sustaining the society we live in; thus if they change there will be societal consequences. Promoting a different view of care needs may have many positive outcomes. Interdependence and autonomy have emerged as possible alternative discourses. However, the potential for negative consequences, such as an increased demand for help from a generation that feels entitled to this, would create its own problems. That does not mean change is not needed but that the consequences of such change also need to be considered.

**References**


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