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Loss and profound learning disabilities: The significance of early separation responses

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Abstract

Purpose Learning disabilities may complicate the experience of bereavement and loss, in those with communicative impairments compounded by complex healthcare needs and sensori-motor limitations. Whilst theorists have argued that the cognitive difficulties of people with profound learning disabilities impede mourning reactions, none have attempted to make sense of the responses they do exhibit. *Approach* A select review considers the neurophysiology underlying attachment bonds, complications in attachment formation and affect regulation in people with LD, and separation responses of people with profound learning disabilities. *Findings* The current paper demonstrates that by recognising the affective nature of separation distress, an understanding beyond a cognitive conceptualisation is possible. *Research implications* It is worth questioning whether people with profound learning disabilities are incapable of any *meaningful* form of person permanence. A critical review could deal with this comparatively by drawing on research of person and object permanence in typically developing children. *Practical implications* Of specific interest, the bio-behavioural regulators of relationships may help us to appreciate the importance of routine physical health and social care for emotional wellbeing in this group. *Value* It is argued that by appreciating the basic emotional and regulatory functions of relationships, we can achieve a greater insight into the loss experiences of people with profound learning disabilities that will offer therapeutic direction.

Keywords: attachment, separation, profound learning disabilities, loss, care, neurophysiology

Loss and profound learning disabilities: The significance of early separation responses

Loss may be felt as one of the most painful experiences. Fortunately, most adults adjust to separation from a loved one without the enduring effects of trauma (Bonanno, 2004). Learning disabilities (LD) may complicate this, those in particular with communicative impairments compounded by complex healthcare needs and sensori-motor limitations (Pawlyn and Carnaby, 2009). As many as 80% of people with profound LD experience at least one severe sensory impairment, alongside health related conditions including epilepsy, respiratory problems and mobility limitations (Nakken and Vlaskamp, 2007). Communication skills are significantly compromised and often restricted to vocalisation, facial expression and limited movement. Whilst theorists have argued that the cognitive difficulties of people with profound LD impede mourning reactions (Meeusen-van de Kerkhof *et al.*, 2006), none have attempted to make sense of the responses they do exhibit. This is an important argument because bereavement support will be greatly shaped by the extent to which caregivers perceive the individual as experiencing loss (McEvoy *et al.*, 2010). That separation responses originate from neurobiological systems is hugely significant for understanding loss emotions. Though it may be difficult to engage with the subjective lives of people with profound LD, neurophysiological research is informative, and elaborates on the loss experiences of all human beings, regardless of cognitive capacity.

This current paper demonstrates that by recognising the affective nature of separation distress, an understanding beyond a cognitive conceptualisation is possible. First, research into neurophysiology underlying attachment bonds is rendered relevant and questions our emphasis on cognitive aspects of grieving. Second, complications in attachment formation and affect regulation are identified in people with LD. Third, separation responses of people with profound LD are recognised in terms of their affective nature. This paper facilitates reflection on the limitations of a cognitive framework that neglects to consider the affective nature of human beings. Affective neuroscience has scarcely been applied to the LD field, despite far reaching relevance. In addition, it is argued that by appreciating the basic emotional and regulatory functions of relationships, we can achieve a greater insight into the loss experiences of people with profound LD that will offer therapeutic direction.

Neurobiological perspectives on attachment and separation

From an attachment-based perspective, behaviour seeking to establish contact with the mother - and indeed responses to separation from the mother - are intrinsically motivated to promote survival of the vulnerable infant (Bowlby, 1969; 1973)¹. Bowlby (1969) described this attachment-seeking system as serving the functional means by which to achieve homeostasis. The

¹ Of course, many have criticised Bowlby's (1969) apparent gender bias.

instinct to form and maintain relationships may then be more or less conditioned by learned experiences within the environment, and more crucially relational interactions. The devastating impact of maternal separation demonstrated in early human infancy (Robertson and Robertson, 1971) and in animals (Harlow and Zimmerman, 1959) is central. Bowlby (1973; 1980) suggested that the protest responses (e.g. crying) of infants to these separations are innate, serving to bid strongly for the mother's proximity and care, leading to despair and detachment if not met with an appropriately matched response. Exploration of the specific mechanisms that give rise to these responses however was left for scientific study.

Arguably, some of the most important advancements in neuroscience have emerged from studies with animals². These have revealed a number of insights into human emotion, which is enhancing our understanding of trauma and healing (e.g. Fosha *et al.*, 2009). For example, in Panksepp and Biven's (2012) contribution of the seven affective systems in the mammalian brain, we can further appreciate the adaptive neurophysiological mechanisms underlying, among other aspects, social bonds. These include seek, rage, fear, lust, care, panic/grief and play. The question of whether their related affects are phylogenetically recent – as purported by LeDoux (2002) among others - or deeply rooted in the subcortical history of humans and animals - as Panksepp and Biven (2012) would suggest - is currently a matter of debate. Whatever the outcome, it will be relevant to people with early loss of or damage to cerebral hemispheres. More specifically, to conversations on their consciousness (see Merker, 2007; Shewmon, 1999)³. A multi-layered conceptualisation of consciousness – similar to MacLean's (1990) abridged 'triune brain' - allows us to consider the presence of consciousness at the affective and perceptual levels in this group (Davis and Panksepp, 2011; Panksepp *et al.*, 2007).

Within Panksepp and Biven's (2012) review of affective neuroscience, separation distress is mediated primarily by the panic/grief system, the evolutionary history of which may relate to place attachments and thermoregulation (Panksepp, 2004). Furthermore, this system is related to the same brain chemistry regulating pain (Herman and Panksepp, 1981). Protest, searching and crying all have clear survival functions⁴ and painful affects. This has been partly supported by a range of studies, one particular entitled *Does Rejection Hurt?* (Eisenberger *et al.*, 2003), demonstrating activation of the anterior cingulate cortex during social exclusion, which correlated with self-reports of psychological pain. The despair phase of separation conserves the body's energy and reduces the

² It is worth noting that one does not, even implicitly, attempt to draw comparisons between animals and people with LD on the basis of cognitive deficits. I am fully aware of the philosophical and political implications of this (see Kittay, 2009). The purpose of these comparisons is rather to highlight the core affective nature of human beings.

³ A discussion of these issues will feature in my PhD thesis (reference here will be anonymous until after review process)

⁴ A first glance of this work may seem reductionist. However, a close reading of this work reveals a resistance to reductionist evolutionary psychology.

likelihood of further loss and danger to the infant (e.g. by inhibiting separation calls), partly mediated by the brain's natural opioid resources (Panksepp, 1981). Theoretically, the behavioural responses to separation are a clever adaptation evolved from very early brain centres that guide survival. Thus, separation for a temporary or indefinite time, actual or perceived, may provoke painful experiences for the young infant, which result in a range of behavioural reactions.

In addition to these offerings, Hofer (2006) has led a carefully crafted programme of research identifying some of the precise physiological mechanisms giving rise to the protest and despair phases outlined by Bowlby (1973). His earlier research reveals that discrete aspects of the caregiver's input regulates specific bio-behavioural features of the infant. Maternal separation in small mammals resulted in distinct behaviours (e.g. crying, activity levels) and physiologic changes (e.g. heart rate, weight gain) in the pup, found to be responses to the removal of particular elements of the mother's interactions (e.g. warmth, tactile stimulation, the mother's milk). If these elements were substituted (e.g. with a familiar littermate) then protest responses in the pup (e.g. conservation-withdrawal) were at least overtly inhibited, although despair responses (e.g. conservation-withdrawal) ensued. Therefore, protest and despair are in fact comprised of several bio-behavioural responses when distinct regulatory aspects of the mother are removed, and are commonly lost all at once during separation. This has major implications for how we understand separations early in life, into adulthood and in relation to grief (Hofer, 1984). Alongside the immediate sense of danger and the painful break in the affective bond, loss is also a withdrawal of key regulators.

Hofer (1984) agreed that human connections are much more complex than his studies would suggest. For example, we do not yet know how these regulatory elements of relationships may translate into internal representations. It is argued that relationships are internalised beneath the level of conscious awareness and take the form of secure or insecure attachment schemas (Waters and Waters, 2006). These core representations are generalised from interactions with the primary caregiver, and may be drawn upon for self-regulation, and in order to make inferences about future social interactions (Stern, 1985). They are not necessarily linguistic-declarative schemas; implicit-procedural memory may be involved in their formation (Schoore, 2001). Early relationships are therefore critical, not only to the development of attachment representations, but also related affect regulation. Sensitive and reciprocal interactions, which characterise secure attachments, are necessary for the shaping of the right-brain: of self-regulatory systems (Schoore, 2001). Development of an infant's stress system is grounded in the communications between the infant and their caregiver. Substantial ruptures in this attachment bond, and in particular those that elicit fear/and or pain, are deleterious to wellbeing and functioning (Schoore, 2003). Attachment theory is now one of regulation as a result of the last two decades of this brain research focussing on critical

periods of development within the context of interpersonal interactions. What this suggests in relation to loss, that the emotional and behavioural responses to separation have a neurobiological bases and can be considered in terms of their defensive abilities and affective experiences.

Attachment and learning disabilities

Discourse has perhaps overly relied on the relevance of cognition in understanding the experience and complications of grief in people with LD (Young, 2016a). More recently, attachment theory has gained considerable merit in providing a theoretical approach to bereavement and loss (Dodd & Blackman, 2014), and has been practiced to ameliorate separation anxiety in people with LD (Sterkenburg *et al.*, 2008; Jonker *et al.*, 2015). For a number of reasons, forming secure attachment relationships with caregivers are met with extreme difficulty for this group. The prevalence of separation anxiety is therefore higher than in their typically developing peers (Emerson, 2003). A weaving of interactional factors may give rise to this, including affect dysregulation, psychopathology (Schuengel *et al.*, 2006) and insecure attachment relationships (Clegg and Sheard, 2002; Clements and Barnett, 2002). This combination, within the wider context of societal and cultural issues affecting people with LD, is believed to contribute to significant difficulties with loss experiences (Blackman, 2016). Dodd and Kelly (2016) argue that separation distress is at the core of this ‘complicated grieving’. It is expected that people with profound LD will also experience similar problems, contributing to anxiety when separated from the caregiver and complicated grieving following permanent loss. However, there are two concerns, which direct us to consider people with profound LD beyond this.

First, bereavement and loss literature and practice has generally failed to consider the experience of people with profound LD and their support needs (Young, 2016a). Within the limited literature, they are assumed to show no mourning responses (e.g. crying), but display behavioural reactions to the consequential disruptions of loss (Meeusen-van de Kerkhof *et al.*, 2006). Some of the limitations of this approach have already been discussed elsewhere (Young, 2016b). More specifically, this discourse has neglected central issues of attachment and stress, and is insufficient in accounting for the apparent range and complexity of responses to separation among this group (for a review, see Young, 2016a). Second, the majority of interventionist research conducted with theoretical direction from attachment and stress regulation has concentrated mainly on levels up to severe LD (see Schuengel *et al.*, 2013 for a review). These studies demonstrate plasticity of social-affective behavioural systems in this group, and in those with early attachment disruptions. One questions whether the same successful outcomes cannot also be observed in those with profound LD. Perhaps it is the concern of compromised person and/or object permanence (Jonker *et al.*, 2015; Sterkenburg, 2008), thought to be a pre-requisite for secure attachment (Sappok *et al.*, 2013), that questions applications of this therapeutic work to the profound LD group. Undeveloped

awareness of the caregiver's on-going existence can give rise to separation anxiety in securely attached infants (Ainsworth *et al.*, 1979), but is suggested as persistent in people with LD (Bricknell and Munir, 2008) and in particular severe and profound LD (Janssen *et al.*, 2002). Although a full consideration of these concerns is beyond the scope of this paper, it is worth bearing in mind that bereavement and loss work with people with profound LD has been largely inhibited by a preoccupation with the 'cognitive'. It will therefore be useful to first explore the separation responses of people with profound LD and make sense of these in light of their affective nature.

Separation responses of people with profound learning disabilities

Research has pointed to the role of interpersonal trauma, and in particular bereavement and loss, as a risk factor for poor emotional wellbeing among people with profound LD (e.g. Sinason, 1992; Phillip *et al.*, 2005). Separation responses are fashioned within a historical context of attachment and separation experiences, representations of the attachment, and stress vs resources (including other regulatory relationships). We know very little about the nature of social bonds in people with profound LD, however. They have no way of effectively sharing the quality of their experiences; we must infer their states and preferences from their behaviour. This group has been excluded from a number of studies on attachment due to their sensory and motor impairments, which render the nature of the relationship unclassifiable in the 'Strange Situation' paradigm (Marvin and Pianta, 1996). Panksepp (2004) suggests that exploring sorrow and grief may be one of the most powerful ways of revealing the formation and nature of attachment relationships. It is perhaps this area of bereavement and loss that will also help guide an understanding of those bonds in people with profound LD. We can thus consider something of their attachment relationships on the basis of their responses to separation from these.

Only a small number of studies have been alert to the separation responses of people with profound LD. The limited research, as reviewed in Young (2016a), is therefore of significant interest. In those experiencing separation, clinging to the attachment figure and looking/calling for the deceased have a clear purpose of establishing contact and proximity with the caregiver. In addition, challenging behaviour and self-harm may be present. The stress-attachment model, devised by Janssen *et al.* (2002), suggests that challenging behaviour in this group serves a regulatory function for high levels of stress. This, in some ways, is an extension of the view that challenging behaviour is a protest response that aims to establish contact with the secure regulatory base (Clegg and Lansdall-Welfare, 1995; Clegg and Sheard, 2002). Furthermore, the despair phase of separation can be characterised by loss of abilities, loss of appetite and complete withdrawal. Unfortunately, these observations lend little insight into their related emotional experiences. Again, emotion must be inferred from behaviour. For example, Dosen (2010), however, suggests that the

aggressive behavioural reactions emerge primarily from the fear initiated by separation, and this may be further extended to include panic and grief (Panksepp and Biven, 2012).

The need for valid and reliable assessments of mood in people with profound LD (Ross & Oliver, 2003) has led to developments in identifying subjective wellbeing. A group researchers have employed physiological measures of respiration, skin conductance and heart rate against emotional valence indicators (Vos *et al.*, 2010). Lyons *et al* (2013) add startle reflex modulation – a measurement of muscle contraction around the eye - as a potentially valuable contributor to this research programme. Against this backdrop, a number of studies have indicated psychophysiological responses to separation and loss in people with profound LD. Chaney's (1996) study of stress revealed that removing the person from their home environment, and from their attachment figure, resulted in reactivity of one or more of the following: heart rate, blood pressure, respiration rate and body temperature. In addition, Dosen (2005) reports a young boy experiencing temporary separation from his mother and changes to his environment that resulted in dysregulation across the bio-psycho-social system. A similar result is described by Shewmon *et al* (1999), who report a range of behavioural and biological responses of young children with hydrocephaly to brief separations from their mother. Of particular interest is the case of a young boy requiring hospitalisation for airway obstruction. The mother's voice was observed to be a direct regulator of the child's oxygen saturation; if she withdrew her voice, oxygen saturation destabilised. In line with Hofer's (2006) view, the observed behavioural and biological changes are the direct result of absent maternal-regulators.

Regulating Care of Complex Needs

A thorough review of the care and support of people with profound LD would reveal a variety of ways in which parents and carers maintain health and quality of life in this group. Pawlyn and Carnaby (2009), for example, examine the complex topics of mental health, epilepsy, respiratory health, nutrition, dysphagia and postural care. Use of technological equipment may be required to assist with these in addition to sleeping, communication, moving and handling, toileting, positioning, and medication among others (Nicholl *et al.*, 2013). Relying on 24-hour care, people with profound LD require skilled and attuned carers, which is commonly provided by parents of people with LD into their elderly years (Hubert and Hollins, 2000). We may expect that the intense level of care will play a significant role in regulating emotion and physiology of the person with profound LD, in ways that compensate for the disability. For example, mothers of children with cerebral palsy use more proximal behaviour (e.g. close physical contact) compared with mothers of children with other congenital and developmental disabilities (Brooks-Gunn and Lewis, 1984). The frequency and regularity of everyday tasks may be extremely important for the wellbeing of this group, resulting in dysregulation if even minimally disrupted. Furthermore, regulation may not just

result from interpersonal interactions, but by familiarity with the environment in which that intimate care takes place (Gibson *et al.*, 2014). The issue of placement is therefore a crucial one to people with high dependency and complex healthcare needs. Within Hofer's (2006) framework, independent self-regulation may not exist in typical adults, but is instead mediated by relationships. This is most certainly the case in the profound LD group.

Implications

Traditionally, bereavement and loss have been conceptualised as life events (e.g. Hastings *et al.*, 2003): disrupting the attachment bond, causing significant stress, and which the person with profound LD cannot understand (Meeusen-van de Kerkhof *et al.*, 2006). This conceptualisation requires the reflection that loss is the ending of a unique relationship that provided essential care for physical and emotional wellbeing, and which provided feelings of security and safety to the person. Perhaps the behavioural manifestations of emotional stress in people with profound LD are too often easily dismissed as challenging behaviour, and their apparent non-response as indifference, without consideration of the underlying experiences of painfully felt emotion. We should therefore be careful to consider the nature of their loss (Hofer, 2004) and how that impacts on the emotional and the 'body lives' of people with profound LD. In relation to bereavement support, the careful attunement of an attachment figure will be of therapeutic value to persons with profound LD. We must connect with people with profound LD in consistent, frequent and predictable ways. Considerations of transition – from school to adult service or a move from home – must be carefully planned and met with sensitivity to healthcare needs (McBride and McDicken, 2012). These will also provide opportunities to develop neurobiological capabilities and increase health and happiness.

In conceptualising loss in terms of neurophysiology, it enhances the stress-attachment model of challenging behaviour (Janssen *et al.*, 2002) by suggesting that there may be specific regulators within the relationship that the person with disabilities is responding to when loss occurs. Research has yet to establish whether careful and attuned therapeutic contact can enhance affect-regulation in those who have profound LD, which will have undermined this development. In addition, to what extent can current or new caring relationships establish regulatory interactions, not as a replacement of a lost loved one, but that can serve a similar regulatory function? And, how can we support these relationships with what we know from the literature reviewed here? In addition, this paper has tentatively raised the concept of 'person permanence'. It is worth questioning whether people with profound LD are incapable of any *meaningful* form of person permanence or other representation for secure attachments, as this will have implications for therapeutics. A critical review could deal with this comparatively by drawing on research of person and object permanence in typically developing children.

Conclusion

This paper aimed to display the value of theoretical and empirical research that recognises the affective nature of separation. Research and practice face significant challenges in engaging with those with the most complex of needs, which are only further complicated by a cognitive framework that limits our ability to appreciate their emotional lives. We possess an abundance of research into our affective natures (Panksepp, 2012). Hofer (2006), for example, has intelligently observed the inherent nature of relationships to regulate our bio-behavioural existence. Bio-behavioural regulators may be even more critical in the context of high dependency and complex healthcare needs. This does not reduce the view that loss is a break in the affective bond, but instead enhances that view by honouring the richness of the relationship that existed before it. We should listen to that story of neurobiology to assist us in meeting the social, emotional and physical needs of people with limited cognitive abilities. In seeking to meet these challenges, I have endeavoured to expand the field's conceptions of bereavement and loss in people with profound LD. The result suggests that interventions, which support the development of attachment formation and regulation, should be one of the core aims of bereavement support.

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