

Caregiver burden & distress in families with ABI in Ireland

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Incidence / epidemiology of Acquired Brain Injury in Ireland

- **Acquired Brain Injury (ABI)**. Data from the Hospital In-Patient Enquiry (HIPE) System, indicate that in 1997 there were **10,980 hospital admissions in Ireland involving ABI**. There were 7615 males and 3365 females. The average age of the males was 27 and of the females was 30 (Waldron & Grimson, 2000).
- The Phillips Report (2008) covering Beaumont & Cork University Hospital **gave an annual number of 1275 people with TBI requiring specialist neurosurgical services**.
- **Cerebral Vascular Accident (CVA)**. The RCSI & ESRI (2010) indicate that in 2007 there were 5,834 people with stroke discharged from acute hospitals with stroke.

Study 1 – Families accessing ABI Ireland or Headway in 2008

Using Pearlin's Stress Process Model (SPM; Pearlin, 1989), Joanne O'Halloran (2008) examined factors likely to have an impact on the adjustment of family caregivers who were accessing services either via ABI Ireland or Headway. A total of 76 carers participated. The average age of respondents was 48.55 years. There were 69 Females and 7 Males.

The SPM was designed to assess the informal caregiving processes affecting caregiver health. Pearlin et al. (1989) argues that caregiver stress should be viewed as a mix of circumstances, experiences, resources, and responses that vary among caregivers and consequently will vary in how they impact on the caregiver's health and behaviour. **The SPM conceptualises caregiver stress as a product of four interrelated factors:**

(1) The background and context of stress include characteristics of the caregiver such as age, gender, and educational, occupational, and economic attainments.

(2a) Primary stressors include one's family member experiencing an ABI and the caregiver's subjective perception of overload/burden. Primary stressors are durable over time and are productive of secondary stressors which emerge as a result of having a family member with an ABI.

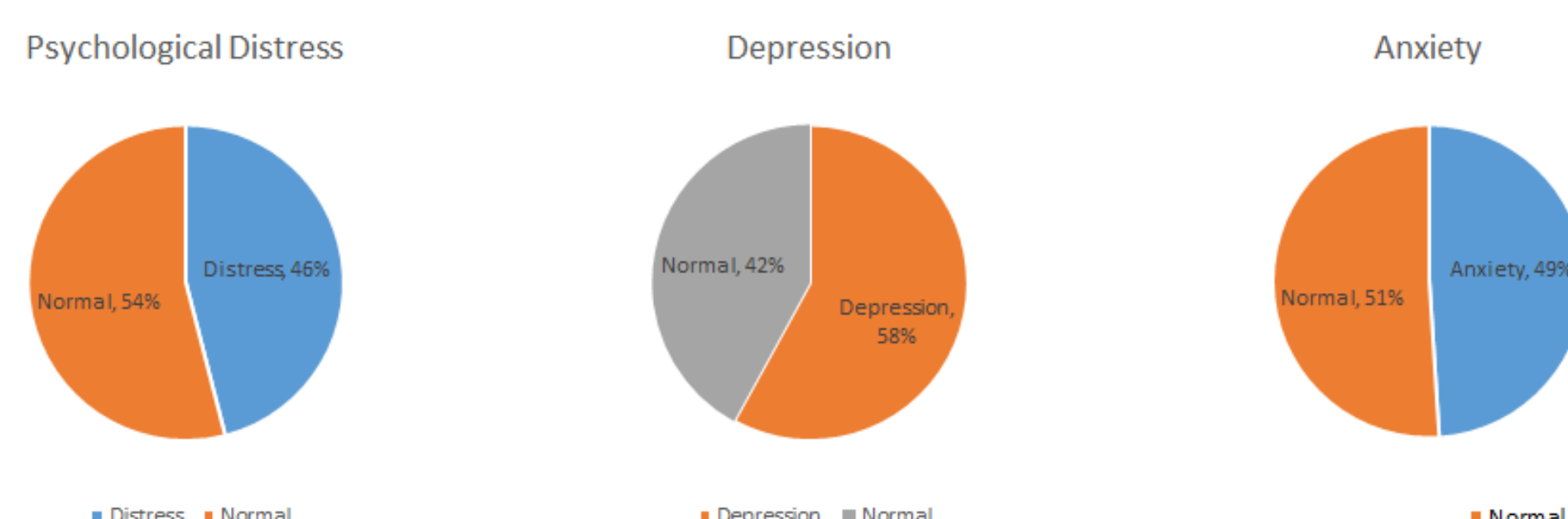
(2b) Secondary stressors are distinguished as comprising *role strains* or *intrapsychic strains*. Secondary role strains are those areas of life that may be compromised as a result of the caregiving role and they include those roles and activities outside the caregiving situation (e.g., the family, occupation).

(3) The mediators of stress; "coping" and "social support" are regarded as two of the principal mediators in the caregiving literature, each impacting on the overall outcome.

(4) Outcomes of stress included measures of anxiety; depression and overall distress measured using the Symptom Checklist 90 Revised (SCL-90-R; Derogatis et al. 1994).

Symptom Checklist 90 Revised - Results

- **46% of the sample of 76 people reported clinical levels of psychological distress.**
- **58% exceeded the cut-off for depression.**
- **49% exceeded the cut-off for anxiety.**



Overall, the areas of the Pearlin stress process model that significantly explained variance in respondents outcome scores included objective primary stressors (i.e. amount of care provided), subjective primary stressors (i.e. subjective caregiver burden), and stress mediators (i.e. coping and social support).

Conclusions and Implications

This study highlights how all family members of individuals with ABI are a population at risk. It is imperative that clinicians who develop and deliver rehabilitation programmes for individuals with brain injury, take into consideration the effects of the injury on the whole family and further develop rehabilitation programmes that aim to better enhance families with skills necessary for successful adaptation post-injury.

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Study 2 – Survey during the ABI Ireland Carers' Conference in 2017

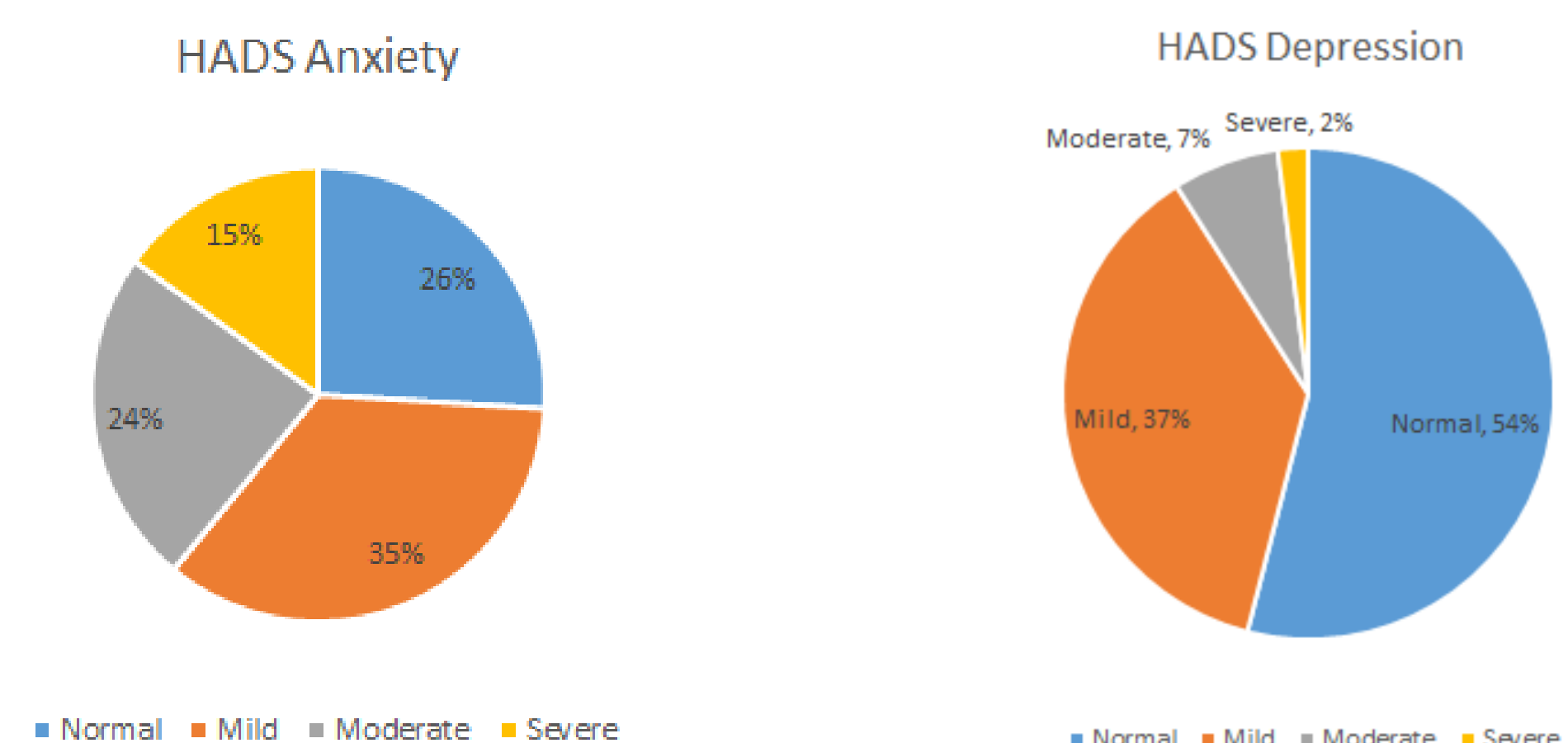
As part of the ABI Ireland Carers' Conference, 45 Irish carers rated the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and 1 person with a brain injury rated the scale, for a total of 46 responses. The average age of respondents was 59.9 years. There were 44 Females, 08 Males, and 01 person who did not report their gender. Including or removing the person with the ABI (a male) did not significantly change the means or totals for the groups on any analysis.

HADS Anxiety Scale - Results

The average rating across all responses was within the mild range for anxiety (total = 10.10). This places the overall sample who responded about 1 standard deviation above the mean for the general population for anxiety ratings. On the anxiety sub-scale, 12 people (26%) were within the normal range, 16 people (35%) were within the mild range, 11 people (24%) were within the moderate range, and 7 (15%) people were within the severe range. The percentages within the mild, moderate and severe ranges for anxiety are elevated compared to the general population (Crawford, Henry, Crombie & Taylor, 2001).

HADS Depression Scale - Results

The average rating across all responses was at the upper end of the normal range for depression (total = 6.97). This places the overall sample who responded around 1 standard deviation above the mean for the general population for depression ratings. On the depression subscale, 25 people (54%) were within the normal range, 17 people (37%) were within the mild range, 3 people (7%) were within the moderate range, and 1 person (2%) was within the severe range. The percentages within the mild, moderate and severe ranges for depression are elevated compared to the general population (Crawford, Henry, Crombie & Taylor, 2001).

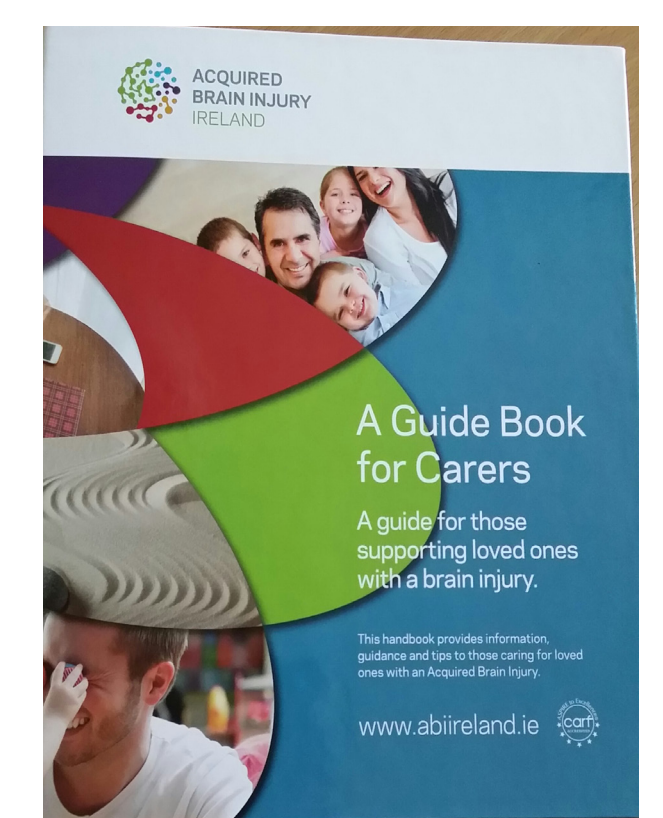


CSI – Caregiver Stress Index - Results

The Caregiver Strain Index (CSI; Robinson, 1983) is a measure used to screen for caregiving stress. There were 50 valid responses from carers at the conference and the average score for the group was 7.94, above the cut-off indicating that the group overall were experiencing significant burden related to their role as caregiver.

Conclusions and Implications

The conclusion is that the carer sample that responded on the day are exhibiting higher levels of self-reported anxiety and depression on a psychometric measure that is well-validated in the general population, and are experiencing very significant caregiver burden.



Supporting carers – how ABI Ireland is responding

- Provision of face-to-face family carer training programmes (N= ~250)
- Provision of information and resources (Family Carer Handbook)
- On-going support through family carer support/peer groups across Ireland
- Recognition of family carer role in the rehabilitation process
- Awareness raising and advocacy on ABI carer issues

