ANZBA 2018

Rising to the Challenge of Long-term Follow up Research in Burns : Reducing attrition

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CRICOS Provider Number 00025B

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Longitudinal, prospective study of long-term burns outcomes

Predictor Variables	Outcome Variables
• Injury factors • Treatment factors • Personal factors • Environmental factors	• Psychological outcomes • Social outcomes • HRQoL outcomes • Life Satisfaction • QALYs

Participants N=274
Hospitalised adults post-burn in an Australian context

Methodology
- Interview-based pre-injury data collected within 28 days of burn (8 minutes)
- In-person or phone interviews at;

Time-point Post-burn	Interview Duration (Mins)	N (attrition)
3 months	20	213 (22%)
6 months	20	203 (26%)
12 months	30	196 (28%)

Data Retention Procedures

- Burns unit staff verbally introduced/explained the study rationale
- Purpose and specific requirements detailed by the researchers at recruitment
- SMS reminders 1 week before 3-, 6- and 12-month follow ups + 4 weeks before 12-month follow ups and invited to pre-schedule interviews
- Researcher attendance at outpatient clinic for reminders and data collection.

Strategy Rationale

- Legitimacy, trust and confidence due to clinical staff involvement
- Realistic expectations
- Participants 'primed' for follow up contact
- Participant control over interview scheduling
- Personalised contact between time-points

Pitfalls

- Tendency to consider withdrawing if feeling "too well" to add value
- Participant burden if enrolled in other studies
- High decline rate for those with concurrent stressors (eg. injured children/property loss)
- Unable to determine reasons for loss to follow up unless relatives responded to messages (eg deceased/incarcerated)
- **Time intensive +++**

Tips for Data Retention

✓ Increased 'buy-in' at recruitment and follow up by presenting 'values-based' purpose of the study and regular expressions of gratitude.

✓ Attendance at outpatient clinics for increased visibility, reminders and opportunistic data collection if agreed.

✓ Telephone or in-person contact vs mail-out methodology increased participant engagement.

✓ Same researcher at each time-point increased rapport and personalised connection.

✓ Facility for interview scheduling outside of business hours.

✓ Conveying to participants that their experience "matters" – for many, the research contacts were their sole opportunities for validation of injury impacts.

The challenge of longitudinal researchers is to harness participants' needs for validation, based on the establishment of authentic and mutual connection, in order to ensure data retention and reduce attrition.

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