

## The acute psychobiological impact of the intensive care experience on relatives

J.M. Turner-Cobb<sup>a\*</sup>, P.C. Smith<sup>a</sup>, P. Ramchandani<sup>a</sup>, F.M. Begen<sup>a</sup> and A. Padkin<sup>b</sup>

<sup>a</sup>*Department of Psychology, University of Bath, Claverton Down, Bath BA2 7AY, UK;*

<sup>b</sup>*Intensive Care Unit, Royal United Hospital NHS Trust, Combe Park, Bath, UK*

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There is a growing awareness amongst critical care practitioners that the impact of intensive care medicine extends beyond the patient to include the psychological impact on close family members. Several studies have addressed the needs of relatives within the intensive care context but the psychobiological impact of the experience has largely been ignored. Such impact is important in respect to health and well-being of the relative, with potential to influence patient recovery. The current feasibility study aimed to examine the acute psychobiological impact of the intensive care experience on relatives. Using a mixed methods approach, quantitative and qualitative data were collected simultaneously. Six relatives of patients admitted to the intensive care unit (ICU) of a District General Hospital, were assessed within 48 h of admission. Qualitative data were provided from semi-structured interviews analysed using interpretative phenomenological analysis. Quantitative data were collected using a range of standardised self-report questionnaires measuring coping responses, emotion, trauma symptoms and social support, and through sampling of diurnal salivary cortisol as a biomarker of stress. Four themes were identified from interview: the ICU environment, emotional responses, family relationships and support. Questionnaires identified high levels of anxiety, depression and trauma symptoms; the most commonly utilised coping techniques were acceptance, seeking support through advice and information, and substance use. Social support emerged as a key factor with focused inner circle support relating to family and ICU staff. Depressed mood and avoidance were linked to greater mean cortisol levels across the day. Greater social network and coping via self-distraction were related to lower evening cortisol, indicating them as protective factors in the ICU context. The experience of ICU has a psychological and physiological impact on relatives, suggesting the importance of identifying cost-effective interventions with evaluations of health benefits to both relatives and patients.

**Keywords:** social support; coping; stress; intensive care; relatives

### Introduction

Recent work has highlighted the impact of intensive care experience on patient psychological morbidity (Griffiths et al., 2013; Wade et al., 2012). Growing awareness exists amongst practitioners that this impact extends beyond the patient to include close family members (Davidson, 2009). Following intensive care admission, relatives are exposed to a potentially traumatic, frequently ‘alien’ environment, specialist staff and technical equipment (Fassier & Azoulay, 2010), invasive medical procedures (Kross et al., 2011),

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\*Corresponding author. Email: [J.M.T.Cobb@bath.ac.uk](mailto:J.M.T.Cobb@bath.ac.uk)

and may be asked to act as ‘proxy’ in life-changing or end-of-life decisions (McAdam & Puntillo, 2009). Staff address relatives’ concerns by accommodating cognitive, emotional, social and practical needs (Verhaeghe, Defloor, Van Zuuren, Duijnste, & Grypdonck, 2005) but may underestimate these (Buckley & Andrews, 2011) and relatives may defer their needs in favour of patient well-being (Hinkle & Fitzpatrick, 2011). Relatives of intensive care unit (ICU) patients report feelings of panic, chaos, and a need for constant vigilance (Linnarsson, Bubini, & Perseus, 2010), high levels of anxiety, depression and post-traumatic stress (McAdam & Puntillo, 2009). Knowledge of coping responses used by relatives during this time is limited, despite well-known relationships between coping and health in other contexts (Turner-Cobb et al., 2010). Psychobiological stress response mechanisms have been extensively examined across many situations (McEwen, 1998) but research directly addressing physiological stress and psychological coping of relatives within intensive care is lacking. This study tested the feasibility of psychobiological methods to assess impact of the intensive care experience on relatives during the first 48 h following admission.

## Methods

### *Design*

Mixed methods concurrent triangulation, simultaneously collected (Creswell, 2009) using interviews, questionnaires and biological sampling.

### *Participants and recruitment*

Relatives of patients admitted to the ICU of a UK District General Hospital, were invited to participate within 24 h. Recruitment was during periods of waiting in the ICU, conducted away from the bedside. Inclusion criteria: relative and patient aged 18–65 years; relative closely involved in patient visits; and patient to have been admitted to ICU following a sudden/unexpected health event (via emergency department or surgery). Out of 32 patients admitted, 18 relatives were excluded (two had no visiting relatives, nine had underlying conditions/taking medication, six failed admission criteria, one lacked English proficiency) and eight declined participation. Six relatives were recruited – four men (two fathers; two brothers) and two women (daughters) of ICU patients, aged 25–64 years. All but one was employed and educational level indicated relatively high socioeconomic status.

### *Measures*

*Semi-structured interviews:* used to facilitate a flexible approach to understand the participant’s perspective and explore emerging topics. Participants were reassured of ‘no right or wrong answers’ that the researcher had a list of topics to discuss but the most important were their experiences. The interview script included questions relating to first impressions of the ICU and availability of people to speak to.

*Self-report questionnaires:* psychological coping (Brief COPE; Carver, 1997) specific to having a relative on ICU; emotion, hospital anxiety and depression scale (HADS; Zigmond & Snaith, 1983); trauma experience (impact of event scale (IES); Horowitz, Wilner, & Alvarez, 1979); and social support network and quality (adapted social support map (SSM); Antonucci, 1985), using a hierarchical series of concentric circles, visually representing perceived ‘closeness’ to social contacts. Biological stress marker:

Salivary cortisol sampled using the Salivette (© Sarstedt) four times per day (awakening, pre-lunch, pre-dinner, pre-bed). Participants recorded self-administered sampling times and medication/sleep details. Samples were stored at  $-20^{\circ}\text{C}$  until analysis (Jessop, Dallman, Fleming, & Lightman, 2001).

### ***Procedure***

Following ethical approval (NHS Research Ethics Committee and Institutional REC), the researcher and member of the medical team introduced the study to relatives. Participants were invited to take part in 'a study to explore the experience of the ICU on patients and their family' and allowed up to 12 h to consider participation. Consent was taken by medical staff within 24 h of patient admission. Questionnaires and Salivettes were provided. Arrangements were made for interview in a quiet room in the ICU, within 48 h of patient admission at a time chosen by participants (centred round patient care with rescheduling for unexpected medical events).

### ***Data analysis***

Interviews were analysed according to interpretative phenomenological analysis principles (Smith, Jarman, & Osborn, 1999); detailed examination of each interview, noting emergent themes and connections, developing a master theme list. All scripts were coded independently by two researchers. Inferential analyses examined associations between psychosocial factors and cortisol using non-parametric Spearman's rho correlation coefficients (2-tailed).

## **Results**

### ***Interview data***

Four themes were identified (Table 1).

#### *The ICU environment*

Relatives experienced pre-occupation in anticipation of ICU arrival. Agitation and distress created upon arrival, locating the hospital and ward, compounded situational frustration and anger (R4). Unfamiliarity with the ICU setting was noted in concern and worry about equipment noise (R2). Provision of clear and pre-emptive communication (R3) or previous ICU experience helped normalise the situation (R6). Relatives with limited experience of acute healthcare settings relied upon TV impression/media images to contextualise their experience (R2<sup>1</sup>).

#### *Emotional responses*

Concern and fear were dominant (R1); uncertainty stemming from a lack of clarity expressed as anxiety, anger and frustration (R4); need to manage emotions was important at initial hospital admission, particularly for male relatives; and juggling emotional responses between family members carefully managed (R3).

#### *Family relationships/dynamics*

Established patterns of communication and closeness of familial roles impacted on interactions and provision of support to patients. Lack of a recent close relationship with the

Table 1. Medians (*M*) and interquartile range (IQR) for psychosocial assessments (*N* = 5).

Measure/subscale	<i>M</i>	IQR
<i>Coping (Brief-COPE)</i>		
Self-distraction	5.00	2.50–6.00
Active coping	4.00	4.00–6.50
Denial	2.00	2.00–3.00
Substance use	2.00	2.00–4.00
Use of emotional support	5.00	4.50–6.50
Use of instrumental support	6.00	3.50–7.00
Behavioural disengagement	2.00	2.00–2.50
Venting	3.00	2.00–4.00
Positive reframing	5.00	4.50–6.00
Planning	6.00	5.00–7.00
Humour	2.00	2.00–3.50
Acceptance	7.00	5.50–8.00
Religion	3.00	2.00–6.50
Self-blame	4.00	3.00–6.00
<i>Emotion (HADS)</i>		
Anxiety	7.00	5.50–14.50
Depression	9.00	5.00–11.00
<i>Post-traumatic stress symptoms (IES)</i>		
Intrusion	15.00	8.00–15.00
Avoidance	8.00	5.50–17.50
Total	23.00	15.50–31.00
<i>Social support (SSM)</i>		
Network	13.00	10.50–19.00
Quality/closeness	60.00	45.00–78.50

patient evoked regret (R1). Family interaction patterns were interrupted by ICU admission and new patterns of support organised, from turn taking with the patient to worry about future care (R1<sup>1</sup>).

### *Support*

ICU staff, family, friends and employers were identified as sources of support. Relatives appreciated information provided by staff and explanation of activities/equipment used (R4), whilst acknowledging staff were ‘busy, obviously’ and expressing difficulties asking what was happening. Uncertainty of the timeframe and lack of information created frustration (R6). Practical and emotional support from family and friends, knowing there was someone they could turn to, reduced worry about managing demands (R4<sup>1</sup>). Previous ICU experience changed the approach to caring by relatives e.g. recalling a time when his daughter was ill and he continued to work, one relative expressed he had ‘never forgiven’ himself and ‘this time I made sure that I’m going to be here’ (R4<sup>2</sup>).

Overall, interviews provided vivid descriptions of the anxiety, concerns and perceived support of the families during the initial ICU admission period.

### *Quantitative analysis*

Descriptive data for psychosocial variables (Table 2) show mild-severe scores for anxiety and mild-moderate for depression (Johnston, Wright, & Weinman, 1995). Impact of event scores was higher than published norms for non-clinical acute stress samples

Table 2. Median and interquartile range (IQR) for salivary cortisol across the day (ng/ml).

Time of cortisol sample	Median	IQR
Awakening	2.31	2.15–7.02
Mid-day	1.25	.69–1.70
6 pm	.68	.39–1.00
9 pm	.40	.36–.54

(Horowitz et al., 1979). Most used situational coping techniques were acceptance, instrumental support and substance use. Social support networks included 8–20 individuals; use was almost exclusively made of the three innermost circles. No sex differences were observed.

Table 3. Participant quotes by theme.

Theme	Participant quote
1. The ICU environment	<p>I didn't know where I was going to park ... where to go ... when I pulled in the main entrance and ... I'm like (sigh) 'I really don't know what I'm going to do here'. (R4)</p> <p>... unless you're in the know you think there's something wrong. ... there's another one (equipment) it's called, always on, and it was flashing red and it was making a noise and it had 'M(fib)', and I thought 'I don't understand what does that mean?' ... to me if it's red there's something wrong. (R2)</p> <p>... it was nice to be told before what to expect 'cos I think it might've been a bit of a shock otherwise ... (R3)</p> <p>... this is the second time that we've done this because our elder daughter four years ago was involved in a very serious car accident and uh, we spent three days just sat in that ICU. (R6)</p> <p>I mean, if you see it on TV, I suppose you, you know, like Casualty and that all on TV, but when it affects someone that, a loved one, you're aware that it's different. (R2<sup>1</sup>)</p>
2. Emotional responses	<p>Panic and worry, and um ... worried that I might be too late to be here ... (R1)</p> <p>I was concerned for my daughter, but I was angry as well that it actually got to this stage. (R4)</p> <p>... all I can do is take it a day at a time at the moment, I'm just concentrating on just doing what I can, ... I say, 'taking it a step as a time'. (R3)</p>
3. Family relationships	<p>Um, I was (close to my Dad) as a young child but not, not so much now, but I think that's made it a bit harder as well, that you, feel like you haven't spent enough time ... (R1)</p> <p>I don't think my mum is very independent, and I worry that if my dad doesn't get better then she, uh, will find it really difficult. (R1<sup>1</sup>)</p>
4. Support	<p>They've been very informative of all what's been going on and you know why they're doing it, and why they need to do certain things. I think that's helped a lot to, to understand what's going on. (R4)</p> <p>They (staff) had a few more procedures to do and then you can see her in uh, around about five minutes, and then twenty-five minutes later we were still waiting. .... It seemed like hours. ... Even if someone has just popped their head around the door and said the um, the team are still with her everything's sort of coming on and it's going to be a bit longer, but no, it's just, they just left you. (R6)</p> <p>We've got a good family and friends around us and you know everybody's saying 'can we do this, can we do that, you know, what do you need?' (R4<sup>1</sup>)</p> <p>I've just said (to employer) that my daughter's very ill and my wife and daughter need support and that's it. (R4<sup>2</sup>)</p>

Average sampling times for salivary cortisol were awakening 06:28 ( $\pm 2$  h 7 min); noon 12:19 ( $\pm 28$  min); afternoon 18:41 ( $\pm 33$  min) and evening 21:38 ( $\pm 39$  min). Values followed a typical diurnal decline (Table 3).

Significant associations were observed between self-distraction and evening cortisol ( $\rho = -1.00$ ;  $p < .01$ ); depression and afternoon cortisol ( $\rho = .975$ ;  $p = .005$ ); avoidance and overall mean diurnal cortisol ( $\rho = .900$ ;  $p = .037$ ); and support network and evening cortisol ( $\rho = -1.00$ ;  $p < .01$ ). Greater use of self-distraction and a larger network were individually associated with lower evening cortisol; a greater depression score was associated with higher afternoon cortisol; and greater trauma avoidance was linked to higher mean cortisol. Variables were not significantly associated with diurnal cortisol change, morning or noon measures.

## Discussion

This study examined feasibility in investigating the psychobiological impact of intensive care experience on relatives. Substantial information was gained from using mixed methods. Interview themes (ICU environment, emotional responses, family relationships, support) were reflected in questionnaire assessment. Issues centred round controllability, anxiety, anger and frustration, positive and negative aspects of family closeness, and support network reorganisation. Social mapping identified a high priority on inner circle supports, with ICU staff frequently central. That depressed mood and avoidance were associated with greater mean cortisol suggests potential for development of enduring stress. Negative associations between social network and evening cortisol confirm physiological benefit in larger support networks in this context. Findings linking coping and cortisol suggest self-distraction as adaptive when confronted with acute intensive care, contrasting with coping in long-term adaptation (O'Donnell, Badrick, Kumari, & Steptoe, 2008; Turner-Cobb et al., 2010). Results represent preliminary indicative findings in a difficult to reach population. Methodological limitations, not least sample size, prompt caution in interpretation. The high rate of relatives declining participation reflects the acutely stressful nature of the situation. Future work requires a larger sample, including relatives of patients with long-term conditions. Longitudinal psychobiological assessment is called for which examines 'return to usual' routines, patterns of adaptation, and longer term outcomes which go beyond these initial acute stress effects observed.

Despite limitations, the current study demonstrates strengths in findings and methodological insight. It provides impetus for future work to develop psychological interventions that may benefit physical health and well-being in relatives of ICU patients.

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