Australian Critical Care 28 (2015) 77–81

Contents lists available at ScienceDirect

Australian Critical Care

journal homepage: www.elsevier.com/locate/aucc

Research paper

The complexities of recruiting bereaved family members into a research study in the critical care environment: A discussion paper

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ARTICLE INFORMATION

Article history:
Received 11 August 2014
Received in revised form
26 November 2014
Accepted 27 November 2014

Keywords:
Bereavement
Research
Ethics
Recruitment
Critical care

ABSTRACT

Research on the effects of stressful events on human health and wellbeing has progressed in recent years. One such stress, bereavement, is considered one of life's greatest stresses, requiring significant readjustment. The Cardiovascular Risk in Bereavement study (CARBER) investigated in detail cardiovascular risk factors during the first weeks following the death of a partner or adult child in the critical care environment. The purpose of this paper is to explore the once held perception that the bereaved population should not be involved in research, using an actual illustrative project. The paper specifically focuses on the challenges regarding acceptability and feasibility of recruitment of recently bereaved individuals from the critical care environment. The question of whether bereaved individuals have capacity to consent to involvement in research immediately after loss is considered. The appropriateness of asking newly bereaved individuals to participate in research immediately after the death of their relative is also discussed. The work of the research team demonstrates that early recruitment of bereaved family members into a research project is feasible and acceptable to participants, especially when a multidisciplinary collaborative approach is employed and a personal mode of recruitment used.

1. Introduction

The Cardiovascular Risk in Bereavement study (CARBER)[1–3] was one of the first studies to investigate in detail cardiovascular risk factors during the first two weeks following the death of a spouse/partner or adult child by prospectively examining the complex physiological and emotional responses to bereavement following death in the critical care unit. While death is a natural part of the life process and is a universal experience, the effect of the loss of a spouse, partner or child can be traumatic for the surviving significant other and results in increased health risk, especially in the early weeks and months of bereavement.[4] Despite a large body of evidence of increased cardiovascular disease during bereavement, particularly in the first six months,[4,5] until recently, there had been little work published on the actual physiological and psychological changes that occur in the early days and weeks, especially following death in the critical care setting.

The purpose of this paper is to explore the once held perception that the bereaved population should not be involved in

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http://dx.doi.org/10.1016/j.aucc.2014.11.002
1036-7314/

research, using an actual illustrative project. The paper specifically focuses on the challenges regarding acceptability and feasibility of recruitment of newly bereaved individuals from the critical care environment. Importantly it highlights the role of the multidisciplinary team, with a particular focus on the major contribution made by members of the social work and chaplaincy teams in the initial study design, recruitment of research participants and the ongoing consultative role provided to co-researchers throughout the study. The complex ethical and moral implications that were considered for clinicians involved, to be personally satisfied that the research conduct met their own values and ethics, are discussed. The paper discusses the social worker and chaplaincy discipline-specific psychosocial skills and knowledge brought to the interdisciplinary research team and the implications of the research findings for their practice in critical care.

2. The Cardiovascular Risk in Bereavement study

The aims of the CARBER study were to identify adverse physiological responses to bereavement as potential risk factors for acute coronary syndrome and sudden cardiac death. The study concentrated on evaluating the effects of bereavement on known physiological pathways that have been postulated to precipitate plaque rupture, thrombosis and arrhythmia. Psychological distress (including depression, anxiety and anger), behavioural changes (sleep, appetite, smoking, alcohol and drug consumption) and physical changes (body mass index, waist circumference, cortisol, cholesterol, blood pressure, heart rate and heart rate variability, plus blood clotting factors) were evaluated within 2 weeks of bereavement, with assessments conducted in participants' homes.[1,6] Associations between the psychosocial response and physiological changes were described to explore the nature of such relationships during the complex response to bereavement. The data on the endpoints from bereaved family members of critical care patients were compared to a reference group of participants comprised of relatives of patients who had been hospitalised but did not die. Eighty bereaved men and women, aged 33–84 years, from five public hospitals in Northern Sydney, were enrolled in the CARBER study from 2005 to 2010 and compared to 80 non-bereaved participants.

The findings of the CARBER study advanced the understanding of cardiac risk factors associated with recent bereavement in a sample from the critical care environment; for the first time to our knowledge such a group has been successfully enrolled in a study of this kind. Key findings reported include increased haemodynamic burden (heart rate and blood pressure), altered autonomic function (reduced heart rate variability [HRV]) and a prothrombotic state[1,2,5,6] in addition to the expected increases in measures of anxiety, anger and depression. These findings are consistent with a stress myocardial infarction (MI) model whereby the acute cardiac manifestations of bereavement can precipitate plaque rupture and thrombosis leading to potential coronary occlusion and sudden death.[7,8] Based on these findings, a hypothesis for how bereavement may leads to acute cardiovascular disease was developed (Fig. 1).[5]

3. Recruitment of bereaved participants

Bereaved spouses or parents of deceased patients who met eligibility criteria at the participating institutions were initially approached by a social worker or the Intensive Care Unit (ICU) Chaplain at the hospital, or by a research nurse by telephone within 72 h following the death of their family member. When approached in the hospital setting, interested individuals received a study information sheet, approved by the Human Research Ethics Committee and were informed that they would be contacted by a study investigator by phone. Following this, an appointment was made to conduct an assessment in interested participants' homes during the first two weeks of bereavement (average day 11, range 3–15).

Of those who met inclusion criteria, 60% agreed to participate. Of the 40% who declined participation, approximately half of the refusals were from bereaved spouses or parents, while the others

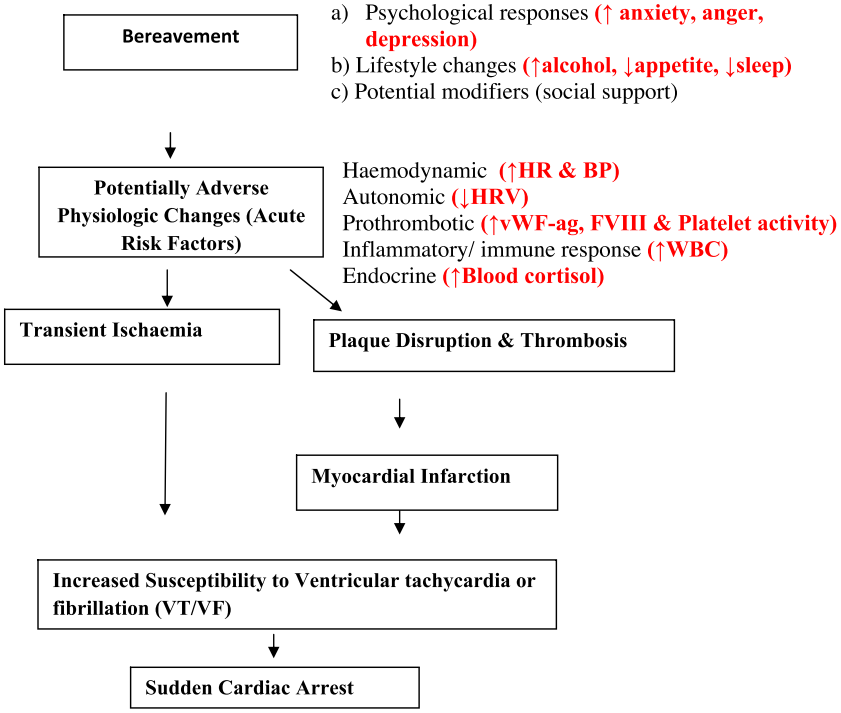

Fig. 1. Representation of how bereavement may trigger MI and sudden cardiac death, based on findings from the cardiovascular health in bereavement study.[5] HR: heart rate, BP: blood pressure, HRV: heart rate variability, VWF-ag: von Willebrand factor antigen, FVIII: factor VIII, WBC: white blood cells.