DISTRESS IN CAREGIVERS ACCOMPANYING PATIENTS TO AN EMERGENCY DEPARTMENT: A SCOPING REVIEW

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Abstract—Background: Despite substantial research interest in caregiver distress in the emergency department (ED), no recent review of the literature exists. Objective: Our aims were to map primary research on caregiver distress in the ED, synthesize key concepts underpinning the literature, identify gaps, and provide guidance for future work. Methods: We used a five-stage scoping review with tandem screening and data extraction. Results: Of 2121 records, 29 studies were included. The majority were small, conducted in North America or Europe, and published after 2000. Numerous methodologies and definitions of distress were represented. The majority involved children, with just five studies restricted to adults. Many involved higher-acuity scenarios, such as resuscitations or invasive procedures. The most common research topic was anxiety of parents of children undergoing procedures. Effects of witnessed resuscitation were also addressed. Parental presence may reduce anxiety during venipuncture, while only waiting room music reduced anxiety in parents of children not undergoing a procedure. No study explored interventions to reduce distress in caregivers of adults. While heterogeneity precluded evidence-based recommendations, clinically relevant observations emerged, including that anxiety can be worsened if a caregiver believes their patient has been forgotten; that parents are sensitive about being perceived as neglectful; and that sympathy and confidence ease distress, as does sensitivity toward end-of-life issues. Several studies suggested that negative staff behaviors affect caregiver anxiety. Conclusions: Future studies should use validated measures of distress; include larger samples; and capture adult, geriatric, and rural populations. A focused systematic review might yield evidence-based guidance for clinicians.

Keywords—anxiety; distress; emergency department; caregivers; families

INTRODUCTION

Studies have shown that caregivers (e.g., partners, children, and parents) of patients in many inpatient settings, including intensive care units (ICUs) and hospital wards, experience significant objective and subjective distress during and after a patient’s stay (1–6). Research suggests that accompanying a loved one to an emergency department (ED) is similarly distressing, particularly when resuscitation or painful procedures ensue, notably in pediatric patients (7). The impact of family presence during resuscitations has been a topic of interest (8). In additional to the ethical obligation to provide comfort and patient- and family-centered care, growing emphasis is being placed on consumer satisfaction in the ED; it is reasonable to expect that families’ experience can have an influence on this increasingly important metric (9). Such factors have motivated development of interventions to mitigate distress, including aromatherapy, ambient lighting, and storytelling (10–12).

A 2003 review yielded insights about caregiver needs, but was conducted by a single reviewer and limited to critically ill patients (13). An updated, broad review is indicated. Our scoping review sought to map primary research on the subject of caregiver distress in the ED, and to identify key concepts underpinning the research area (14,15). We surveyed the quantity, research...
questions, methodologies, and populations of existing research. Such a map may guide future research by informing the selection of research questions, designs, and interventions.

**METHODS**

**Study Design**

Scoping reviews aim to map the literature on a topic or research area by identifying key concepts, gaps, and types of evidence to inform practice, policymaking, and research (16). No consensus definition or procedure exists (14,15). We modeled our approach after Arksey and O’Malley’s iterative six-stage process, which has been widely adopted. We elected to omit the optional sixth stage (consultation exercise) (15–17).

A PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2009 flow diagram depicts stages 2 and 3, including reasons for exclusion (18).

**STAGE 1: IDENTIFYING THE RESEARCH QUESTION**

Based on an informal literature review, we posed the following question: “What are the objectives, methodologies, interventions, populations and presentations of interest, limitations, and directional findings of primary research regarding distress in caregivers of ED patients?”

**STAGE 2: IDENTIFYING RELEVANT STUDIES**

We conducted keyword searches of PubMed, Embase, MEDLINE, CINAHL, and Google for English-language articles published since 1980. We employed the following search structure: (“family” OR “caregiver” OR spouse OR partner OR parent OR loved one) AND (“emergency room” or “emergency department”) AND (“stress” OR “worry” OR “anxiety” OR “fear” OR “distress”); 2121 unique records were located.

**STAGE 3: STUDY SELECTION**

Study selection consisted of title screening, abstract screening, and full-text screening using a priori criteria. The same criteria were used for each phase. Reasons for exclusion at each level are displayed in Figure 1.

**Inclusion Criteria**

Population of study includes caregivers. “Caregiver” includes a parent, child, partner, spouse, loved one, or other family member accompanying a patient in the ED at any point before discharge or transfer to another care setting.

Study discusses caregiver distress. “Distress” includes subjective or objective anxiety, stress, worry, fear, or similar phenomena as experienced by caregivers.

Study is set in an emergency department. “Emergency department” includes any facility specializing in emergency medicine, and excludes, for example, family practices, walk-in clinics, and ICUs.

**Exclusion Criteria**

- Not in English
- Published before 1980
- Invalid study type (not primary research; abstracts)
- Duplicate
- Setting was not an ED (as defined here already)
- Study population did not include at least one caregiver (as defined here already)
- Study did not discuss caregiver distress (as defined here already)

**Title Screening**

One author (TR) screened 2121 titles. One hundred and ten records were advanced to abstract screening.

**Abstract Screening**

Two authors (TR, DM) screened abstracts in tandem. One hundred and twenty-seven abstracts, including 17 records identified by review of full-text citation lists were screened. Thirteen disagreements were reconciled. Fifty-five records were advanced to full-text screening.

**Full-Text Screening**

Two authors (TR, DM) screened 55 studies in tandem. Citation lists of all full-text studies were reviewed for additional records. Seven disagreements were reconciled. Reasons for exclusion are displayed in Figure 1. Twenty-nine studies were included (10–12,19–44).

**STAGE 4: DATA EXTRACTION**

Two authors (DM, AM) extracted descriptive information from the 29 included studies in tandem, as well as
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