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## Home discharge following critical illness: A qualitative analysis of family caregiver experience

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### ABSTRACT

**Background:** Few studies have longitudinally explored the experience and needs of family caregivers of ICU survivors after patients' home discharge.

**Methods:** Qualitative content analysis of interviews drawn from a parent study that followed family caregivers of adults ICU survivors for 4 months post-ICU discharge.

**Results:** Family caregivers (n = 20, all white, 80% woman) viewed home discharge as positive progress, but reported having insufficient time to transition from family visitor to the active caregiver role. Caregivers expressed feelings of relief during the steady recovery of family members' physical and cognitive function. However, the slow pace of improvement conflicted with their expectations. Even after patients achieved independent physical function, emotional needs persisted and these issues contributed to caregivers' anxiety, worry, and view that recovery was incomplete.

**Conclusion:** Family caregivers of ICU survivors need information and skills to help managing patients' care needs, pacing expectations with actual patients' progress, and caregivers' health needs.

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### Introduction

Each year in the United States, more than 5 million individuals experience critical illness that results in admission to an intensive care unit (ICU).<sup>1</sup> Because of improved therapeutics, the majority of critically ill patients survive and many are ultimately discharged home.<sup>2</sup> For patients and family caregivers, home discharge represents positive progress, but also a new challenge. Support from professional care providers is highly variable after home discharge<sup>3</sup> and family caregivers often assume responsibility for needed support.

Improving understanding of – and providing support to – family caregivers of the critically ill has received growing attention. Researchers have begun to examine family caregivers' physical and psychological needs across the continuum from ICU admission,<sup>4,5</sup> to recovery.<sup>6–15</sup> Psychosocial symptoms are most prevalent during the acute phase of patients' illness. According to studies with a one-year follow-up, caregivers of ICU survivors experience depressive symptoms comparable to rates reported by caregivers of patients with dementia.<sup>16–18</sup> High levels of anxiety are correlated with high levels of caregiver strain in the post-discharge period.<sup>19</sup> Prevalence of Post-traumatic Stress increases over time after ICU discharge.<sup>19–21</sup> In a study by Fumis et al. that followed dyads of family caregivers and ICU survivors, depression, anxiety and PTSD symptoms in family caregivers persisted for 3 months post-discharge and were worse than the symptoms reported in ICU survivors.<sup>22</sup>

To date, a limited number of qualitative studies interviewed patients, family members or both to describe their response to long-term recovery following critical illness.<sup>23–25</sup> Cox et al. interviewed 24 family caregivers and 23 patients at varied time points after patients' home discharge (from one to 12 months).<sup>19</sup> These caregivers

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reported feeling distressed by patients' fluctuating emotions and limited support during transition from hospital to home.<sup>23</sup> In a study by Young et al., 20 family caregivers of ICU survivors and 15 family caregivers of elective cardiac surgery survivors were interviewed at 3 months after home discharge<sup>25</sup> and concluded that family caregivers of ICU survivors were more troubled than caregivers of post-cardiac surgery patients because recovery was less predictable. In another longitudinal study, Czerwonka et al., interviewed 7 family caregivers and 5 patients at varied time points which range from 7 days to 24 months post ICU discharge.<sup>24</sup> The study by Czerwonka et al.<sup>24</sup> highlighted following three major points: (1) there is constant and evolving informational needs in this population across the timeline; (2) when informational needs are not met, transition from one care setting to another provokes anxiety and uncertainty in family caregivers; and (3) supporting survivors making transition from dependence to independence needs efforts and negotiation from both ICU survivors and family caregivers. In their findings, home discharge was described as a particularly challenging transition because supports from formal health service gradually decrease and family caregivers begin taking more responsibilities.

Despite importance of supporting needs of family caregivers at varied time points after patients' home discharge, few studies have examined how caregivers' needs and perceptions change over time following home discharge. The purpose of this study was to longitudinally describe the varying challenges and needs of family caregivers of ICU survivors related to patients' home discharge.

## Methods

This descriptive qualitative study involved a content analysis of semi-structured interview data drawn from a parent study that longitudinally examined stress responses in family caregivers of adult ICU patients from patients' ICU hospitalization to 4 months post-ICU discharge.<sup>26</sup> Additional details of the parent study are available elsewhere.<sup>5,8-10,27,28</sup> For this secondary analysis, we included a subsample of interviews with family caregivers who experienced home discharge of patients during 4 months follow-up period. The protocol was reviewed and approved by the Institutional Review Board. All family caregiver participants provided written informed consent.

In the parent study, family caregivers were recruited in the medical ICU of a tertiary university hospital in Western Pennsylvania and followed for 4 months after their respective patient was discharged from the ICU. All baseline interviews were taken place at the ICU. Interviews after ICU discharge were taken place at various post-ICU settings (e.g., long-term acute care hospital) and patients' home.

### Sample

A family caregiver was defined as an individual who provided the majority of emotional, financial, and physical support to a given patient. Neither legal relation nor cohabitation with the patient was required for participation in the study. Eligibility criteria for caregivers were: (1) non-professional, non-paid caregiver; (2) 21 years or age or older; (3) has reliable telephone access; (4) able to read and speak English. Eligibility criteria for patients were: (1) 21 years or age or older; (2) residing at home prior to ICU admission; (3) on mechanical ventilation for 4 or more consecutive days in a medical ICU; (4) not dependent on mechanical ventilation prior to this ICU admission. In this secondary analysis, we used data from 20 family caregivers (1) of patients who were discharged to home during 4 months follow-up period and (2) participated in qualitative interview.

### Interviews and data collection

In the parent study, family caregivers were interviewed by one research team member (JC) at three time points: within 2 weeks, 2 months and 4 months post-ICU discharge. All family caregivers were interviewed face-to-face in places where patients are staying at each time point, except one interview that took place over the telephone. We used a semi-structured interview to ask about the general caregiving experience and its impact on the caregiver's life and relationships with others at each corresponding time point. Each interview started with a question asking about family caregivers' typical day at the time of interview followed by questions asking about caregiving experience and perceived challenges (e.g., "What has been the most difficult thing you have had to help with?"). All interviews were audiotaped for transcription prior to analysis.

### Data analysis

Content analysis was used to determine predominant concepts or text to identify recurring themes consistent with standard qualitative methods.<sup>29</sup> Three research team members (JC, JAT, JHL) independently reviewed first one third of the interview texts. Each conducted line by line coding of their subset of transcripts and identified initial sets of codes for categories that described experiences conveyed by interviewees. The group then met to share and compare coding schemes and category labels using constant comparative analysis to organize the data. Each team member presented illustrative quotes from assigned transcripts, discussed defining properties of each category/theme, reviewed divergent ideas, and finalized themes via group collaboration. Final analysis was conducted independently using stepwise replication. Finally, all transcripts were reviewed to ensure dependability of the analysis.

The team established trustworthiness of these results using standard qualitative strategies.<sup>30</sup> Credibility of the data was secured by prolonged engagement with informants. The group used reflexivity to decrease the likelihood of biased interpretation of the data based on preconceived ideas or experiences. Dependability was obtained by stepwise replication and by maintaining an audit trail. Confirmability was enhanced by using a team of three researchers rather than a single researcher.

Because family caregivers were interviewed at multiple time points following home discharge, emerging themes were organized along three sequences following home discharge: (1) within 2 weeks post-home discharge; (2) within 2 months post-home discharge; and (3) greater than 2 months post-home discharge. Descriptive results are reported with representative quotes.

## Results

### Sample characteristics

In the parent study, we enrolled 47 patient-family caregiver dyads and completed baseline assessment during patients' ICU hospitalization. Among them, 40 patients survived and were discharged from the ICU. Among those 40 ICU survivors, 26 were discharged to home within the 4-month follow-up period. In 26 family caregivers of these survivors, 20 participated in qualitative interview while 6 elected to skip the qualitative interview portion due to time constraints. Detailed information regarding recruitment and retention of sample was illustrated in [Figure 1](#). Only one case was discharge directly from the ICU to home. Transitions to home from post-ICU care settings occurred at varying time points and along different trajectories. Sixty percent of the caregivers (n = 12) participated in interviews at more than two time points.

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