



Communicating Information to Families of Polytrauma Patients: A Narrative Literature Review

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KEY WORDS

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Family caregivers of U.S. servicemembers with polytraumatic injuries (injuries to multiple body systems) need support and information to care for their family members. Providing information to patients' families may reduce stress and increase coping abilities. Because the field of polytrauma research is new and evidence is lacking, providers rely on traumatic brain injury (TBI) research to guide their practice. This article presents a narrative literature review on the information needs of families of patients with TBI. It summarizes the types of needed information, the most appropriate time to provide information, and the best approaches for providing information. Future research on information needs is critical if polytrauma rehabilitation providers are to effectively support families in their caregiving roles. Such research likely will benefit caregivers of patients with polytrauma who acquire their injuries as civilians, as well. Research gaps are identified with regard to the information needs of families of patients with TBI; these gaps also are applicable to polytrauma caregivers. Additional research areas are highlighted in light of the new polytrauma population.

The U.S. Department of Veterans Affairs (VA) provides acute rehabilitation at four polytrauma rehabilitation centers (PRCs; Friedemann-Sánchez, Sayer, & Pickett, 2008) to patients with polytrauma—injuries to multiple body systems or organs including traumatic brain injury (TBI), amputations, multiple fractures, burns, visual and hearing impairment and loss, pain, and posttraumatic stress disorder, among other possible injuries (Lew, 2005; Okie, 2005; Pape, Stalp, Pirente, Neugebauer, & Tscherne, 1999). Before the conflicts in Iraq and Afghanistan, TBI was present in at least 14%–21% of casualties among U.S. servicemembers. In contrast, 62% of patients screened in a recent sample of U.S. servicemembers were found to have TBI (Defense and Veterans Brain Injury Center, 2006). Treating polytrauma is more complex than treating TBI alone because of the constellation and severity of injuries sustained (Friedemann-Sánchez et al.). In a recent study, the majority of patients with polytrauma who acquired their injuries by blast had TBI and a higher number of injuries, compared to those injured by other mechanisms (Sayer et al., 2008). Because the field of polytrauma research is new and lacks detail on best practices, providers rely on TBI-related evidence because rehabilitation is driven by patients' TBI.

The VA's acute polytrauma rehabilitation specialists provide psychosocial support to patients' families. The involvement of family caregivers has been shown to be important for the success of patients' rehabilitation (Lezak, 1988; Marsh, Kersel, Havill, & Sleight, 1998). Families of patients with polytraumatic

injuries need support in caring for their loved one, as well as help dealing with their own stress and anxiety. Previous studies on family caregivers of critically ill patients suggest that providing information on diagnosis, prognosis, treatment, medications, medical facilities, and services can help caregivers cope with crises and reduce stress, anxiety (Burr, 1998; Chiu, Chien, & Lam, 2004; Davis-Martin, 1994; Spatt, Ganas, Hying, Kirsch, & Koch, 1986; Ward, 2001), and uncertainty (Burr). However, no concise summary of research on information needed by family caregivers of patients with TBI has been published to date. Providing knowledge on the types of needed information and the most appropriate timing and communication strategies for sharing this information will help polytrauma healthcare providers work most effectively with family caregivers. Such knowledge may not only result in improved clinical care for polytrauma, but also may guide future research.

This paper presents a narrative review of the literature to synthesize what is known about the information needs of family caregivers of patients with TBI. Implications for clinical practice in the area of polytrauma and priorities for future research also are discussed.

Methods

Narrative reviews, as opposed to systematic reviews (which address a specific question that can guide clinical practice), commonly are broad in scope, making them more appropriate for integrating a wider range of issues on a given topic, identifying

existing gaps in the literature, and generating new areas for inquiry. Because polytrauma is a new area of research that lacks evidence, a narrative review is most appropriate.

Studies or review articles included in this narrative review discussed TBI family caregivers' information or education needs, caregiver-provider communication strategies, communication content, or timing of receipt and delivery of information. The literature was searched in a two-stage process. First, we used Academic Search Premier, MEDLINE, and PsycINFO electronic databases to identify articles. Search keywords were brain, caregivers, carers, closed head, communication, concussion, education, family, head injury, information needs, multiple trauma, needs, open head, pediatrics, polytrauma, traumatic brain injury, veteran, and veteran family. The words "and" and "or" were used to combine keywords and to search for multiple topics simultaneously. The second stage of the search used the "snowball" method. By reviewing citations from key articles retrieved in the first stage, additional articles on TBI caregiver needs were identified. Abstracts from these additional studies were reviewed and full-length articles were retrieved. Articles meeting the inclusion criteria and published in English were then analyzed and synthesized. Articles that were not peer reviewed or published in a language other than English were excluded, as well as articles that focused on patient and caregiver communication, patient needs, clinician needs, and caregiver needs if they did not discuss information needs.

In stage 1, 24 articles on information needs were identified. In stage 2, an additional 26 articles were found. Of the 50 articles identified, 31 did not fit study criteria. Of the remaining 19 articles, 4 were literature reviews, 2 presented educational programs or materials, and 14 were studies (6 quantitative, 7 qualitative).

Results

Table 1 presents a list of all articles reviewed. The following is listed for each article: population; condition studied; method used; and whether the article provided specifics on information content, timing, and delivery. These studies are organized by three primary questions: (1) What type of information is needed and available? (2) What is the most appropriate time to provide information about TBI to families and caregivers? and (3) What is the best format and approach for delivering information?

Type of Information

Most studies addressing information needs have done so within the framework of studying families' overall needs during inpatient care. In four

quantitative studies (Armstrong & Kerns, 2002; Engli & Kirsivali-Farmer, 1993; Kreutzer, Serio, & Bergquist, 1994; Meade, Taylor, Kreutzer, Marwitz, & Thomas, 2004), families were asked to rate their greatest needs; the needs for health information and medical information were rated most important. Kreutzer and colleagues reported a family's greatest needs for information centered on problems in cognition/thinking, caring for traumatic injuries, and recognizing changes in a patient's medical status.

Four qualitative studies assessed family or caregiver information needs (Aitken, Mele, & Barrett, 2004; Bond, Draeger, Mandlco, & Donnelly, 2003; Ramritu & Croft, 1999). Findings such as the need for clear, timely, and accurate information were consistent across both the quantitative and qualitative studies, but the qualitative findings provided more in-depth detail. Ramritu and Croft, for example, reported that caregivers expressed a need for complete information about diagnosis, treatment plans, prognosis, and, of course, recovery. Caregivers wanted to hear the best- and worst-case scenarios; reasons for and results of diagnostic studies; and details about the use of specific hospital equipment, medications, rationale for treatments, and potential patient behavior changes.

A common theme across all articles was a caregiver's need for a clear understanding of a loved one's physical and cognitive condition (Armstrong & Kerns, 2002; Kreutzer et al., 1994; Serio, Kreutzer, & Gervasio, 1995). Caregivers also wanted to understand the purpose of rehabilitation (Holland & Shigaki, 1998) and how the rehabilitation process facilitates recovery (Degeneffe, 2001). Holland and Shigaki found that honest and complete information is needed by caregivers to better understand what is happening to the patient, make the best-informed medical decisions, and have realistic expectations (Holland & Shigaki). In several studies, information on head injury; cognitive impairment; memory loss; and emotional, affective, behavioral, and personality changes were associated with caregivers coping better and experiencing reduced stress (Holland & Shigaki; Junque, Bruna, & Mataro, 1997; Morris, 2001; Ramritu & Croft, 1999; Sinnakaruppan & Williams, 2001).

Families say they need information on how caring for patients with TBI will affect family relationships (Junque et al., 1997). Little information is available regarding how to help families understand and manage changes that occur when a family member has TBI. Few studies have focused on information needs of caregivers beyond the acute rehabilitation stage. Among studies that do exist, Holland and Shigaki (1998) highlighted the need for caregivers to have information about community support services and

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Table 1. The Information Needs of Caregivers with Traumatic Brain Injury

	Type of Study	Population and Condition	Method	Type of Information	Timing of Information	Delivery Mode
Aitken et al. (2004)	Qualitative	16 mothers of patients with TBI	Semistructured focus group regarding general needs		✓	✓
Armstrong & Kerns (2002)	Quantitative	Parents of 19 children with TBI, 21 children with diabetes, and 14 children with orthopedic injuries	Family Needs Questionnaire (adapted)—general needs	✓	✓	
Bond et al. (2003)	Qualitative	7 family members of patients with TBI	No formal instrument; each day of the patient's ICU stay, family members were asked to describe their general needs	✓	✓	✓
Degeneffe (2001)	Literature review	TBI			✓	✓
Engli & Kirsivall-Farmer (1993)	Quantitative	14 relatives (parents, children, spouses) of critically ill or patients with TBI	Critical Care Family Needs Inventory—general needs			✓
Friedemann-Sánchez et al. (2008)	Qualitative	TBI/polytrauma	Semistructured interviews	✓	✓	
Holland & Holland (2002)	Educational materials	TBI	Phase model of pediatric caregiver education and a bibliographic index	✓		✓
Holland & Shigaki (1998)	Educational materials	TBI	Phase model of caregiver education and a bibliographic index	✓	✓	✓
Junque et al. (1997)	Quantitative	65 families (fathers, mothers, live-in spouses, siblings, children) of adult patients with head injury	Questionnaire regarding information needs			
Kreutzer et al. (1994)	Quantitative	119 family members (mothers, wives, fathers, husbands, siblings, girlfriends or boyfriends, other close relation) of patients with TBI	Family Needs Questionnaire—general needs	✓		✓
Leith et al. (2004)	Qualitative	10 patients with TBI and 10 TBI family members	10 broad open-ended questions regarding general needs	✓		
Morris (2001)	Quantitative	34 caregivers (parents and partners) of patients with head injury	Information needs questionnaires completed at T1 and then 3-4 weeks later	✓		✓
Paterson et al. (2001)	Qualitative	7 TBI caregivers and 8 TBI survivors	Semistructured interviews, follow-up phone call	✓	✓	✓
Ramritu & Croft (1999)	Qualitative	34 parents of 28 children with acquired brain damage	Parents described general needs during interviews at three time points: care provided at time of injury, care provided before tertiary care, and care provided after discharge	✓		✓
Serio et al. (1995)	Quantitative	180 caregivers (parents, spouses, siblings, live-in partners, close friends, adult children) of patients with TBI	Family Needs Questionnaire—general needs			
Sinnakaruppan & Williams (2001)	Literature review	TBI			✓	(continued)

Table 1. The Information Needs of Caregivers with Traumatic Brain Injury (continued)

Type of Study	Population and Condition	Method	Type of Information	Timing of Information	Delivery Mode
Testani-Dufour et al. (1992)	TBI	Care plan for families of patients with TBI	✓		✓
Vaccaro et al. (2002)	75 people (50% TBI survivors and 50% their family members)	Focus group regarding general needs		✓	✓
Verhaeghe et al. (2005)	TBI			✓	

school reentry. Techniques on how caregivers can adjust to looking after someone with a head injury, including information on quality-of-life changes and financial assistance, also are viewed as critical information for caregivers and families (Sinnakaruppan & Williams, 2001). Morris (2001) reported TBI caregivers also need information on how to care for themselves.

When Is the Most Appropriate Time to Provide Information?

Three studies addressed information needs at different stages of the inpatient rehabilitation trajectory (Aitken et al., 2004; Bond et al., 2003; Ramritu & Croft, 1999). Although these studies focused on parents of children with TBI, issues about timing of information may help families and caregivers of adult patients with TBI. During the critical phase at the intensive care unit, families want to be kept informed about diagnosis, treatment, prognosis, and reasons for and outcomes of diagnostic tests. They also want to hear explanations about how monitoring equipment works. During acute rehabilitation, information about medications, rehabilitation treatments, and best- and worst-case scenarios is more important (Ramritu & Croft). Families need daily status reports addressing changes in a patient’s medical condition. It is critical that information from different sources be consistent (Bond et al.).

Although research is limited, data suggest that information needs of families during inpatient care are qualitatively different from the needs that arise after discharge. Participants in a cross-sectional study identified discharge as the most useful time to receive information (Morris, 2001). Other studies suggest that many caregivers do not know what questions to ask, what information they will need upon discharge, or what problems they may face; consequently, providing information to families after patients have returned to the community may be best (Aitken et al., 2004; Paterson, Kieloch, & Gmiterek, 2001). Problems that can arise from the lack of relevant postdischarge information are exacerbated by families’ perceptions that rehabilitation personnel have not prepared them for the transition home (Paterson et al.). Aitken and colleagues suggested an exit interview and a 6-week-postdischarge follow-up call to help capture families’ information needs as they arise. Because caregiver distress and worsening family functioning often are associated with the behavioral and affective symptoms of TBI (Junque et al., 1997), this information is needed after discharge, over the long course of recovery, and for several years after the injury occurs.

Holland and Shigaki (1998) propose information be presented during three phases: subacute, acute, and outpatient rehabilitation. Their approach includes delivering information during intensive care

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(the terms and procedures of TBI care), acute rehabilitation (the purpose of rehabilitation, spectrum of possible TBI outcomes, changes in the family system), and outpatient rehabilitation and community reentry (managing behavioral and personality changes, community resources, home health). These researchers emphasize the interdisciplinary nature of both rehabilitation and education and the use of education to compensate for shorter inpatient stays as rehabilitation shifts to outpatient and community settings. They recommend that families not be handed a stack of written materials to read on their own; rather, they should receive information as issues and concerns arise during the long course of recovery so the information is time relevant and comprehensive. The article features a compendium of materials, which later were updated for pediatric TBI (Holland & Holland, 2002), and recommendations supported by a study that suggests caregivers do not recall information provided at discharge—partly because it is not relevant at the time (Paterson et al., 2001).

How to Best Communicate Information?

Two themes emerged from the literature regarding how providers can best communicate information to families and caregivers of patients with TBI: information presentation and information format.

Across the studies, families and caregivers reported that providing clear, comprehensive, and consistent information in a sensitive and empathetic manner is most effective. Families also emphasized the importance of having questions answered honestly, thoroughly, and in understandable terms (Kreutzer et al., 1994). Families of patients with TBI often do not recall information provided during intensive care and acute rehabilitation because of the presentation style or the families' emotional state, among other reasons (Morris, 2001; Paterson et al., 2001; Testani-Dufour, Chappel-Aiken, & Gueldner, 1992). Because family stress interferes with the ability to receive and comprehend information, it is critical to find ways to present information in the least stressful way. Bond and colleagues (2003) suggest information be provided by a designated healthcare provider to reduce stress and ensure message consistency. In addition, information must be presented empathetically using simple language (Aitken et al., 2004; Ramritu & Croft, 1999) and, when possible, with visual aids and written information families can use for future reference (Ramritu & Croft). Provider sensitivity and interpersonal skills, particularly when communicating a diagnosis, can improve family members' ability to cope (Ramritu & Croft); insensitivity can contribute to feelings of guilt and the loss of hope (Aitken et al.; Ramritu & Croft).

In an attempt to make comprehensive information accessible to families and caregivers, several studies recommend providing information using several formats including verbal, written, video, and the Internet. Testani-Dufour and colleagues (1992), for example, recommended that one assigned provider deliver comprehensive information at an appropriate health literacy level in a variety of formats (pictures, written materials, overheads, movies, Internet, and verbal discussions) in an environment conducive to learning.

Holland and Shigaki (1998) suggest written and video information can supplement verbal information and should be provided at each phase of rehabilitation. Vaccaro, Hart, and Whyte (2002) found that patients with TBI and their families use the Internet as a source of information and mutual support, although some family members found the amount of information overwhelming. No articles addressed the need for culturally or gender-sensitive information materials.

In spite of the availability of resources, few studies have tested the effectiveness of any specific educational program or compared different formats of communication. One exception is a study by Morris (2001), who investigated the effect of a booklet designed to reduce family distress that featured information on head injury, cognitive impairment, behavioral and affective changes, and self-care. Study results suggested the intervention was most beneficial to people who are in their first year of being a caregiver (Morris).

Gap in Research Relevant to Polytrauma Rehabilitation

Although much of the knowledge on TBI is generalizable to the polytrauma population, several factors make the information needs of caregivers of patients with polytrauma distinct. The amount and type of medical information families require is complicated by the patients' constellation of traumatic injuries in addition to TBI. Furthermore, the required administrative information is similarly complex because families traverse two systems of healthcare and benefits as patients transition from military treatment facilities and the Department of Defense to VA hospitals and the Veterans Health Administration (Friedemann-Sánchez et al., 2008). After patients are discharged home, families also need information on community resources. To date, there is no research on the specific information needs of this special population.

According to polytrauma providers, the quality, intensity, and type of rehabilitation involvement is different for families of patients with polytraumatic

injuries than for families of patients with TBI. Providers also say that families of patients who are in a coma, semicoma, or who have just emerged from coma appear to have more intense reactions to the patients' condition and more intense interactions with treatment teams than families of polytrauma patients with high cognitive functioning (Friedemann-Sánchez et al., 2008). However, little research has been conducted to determine the information needs of families based on severity of injuries. Nor is there research on the best timing and approach to communicate information based on a patient's level of cognitive functioning. Similarly, the fact that injuries have been acquired in a war context by blasts produced by improvised explosive devices is meaningful to patients and caregivers and is, according to polytrauma providers, an important component of the rehabilitation process (Friedemann-Sánchez et al.). However, the ways in which the context of the injury affects the needs of polytrauma family caregivers remains unknown.

Polytrauma rehabilitation providers in this same study (Friedemann-Sánchez et al., 2008) also reported that family caregivers respond and adjust differently depending on family composition and kinship to patients. Supporting this finding, one TBI study suggested that spouses have more unmet information needs than parents when patients have more physical problems (Serio et al., 1995). To date, no research is available on TBI that addresses different information needs of family members according to gender.

Discussion

Clinical support of polytrauma families draws most heavily from the TBI research on information needs of families during acute inpatient rehabilitation. Numerous TBI studies have identified that, during acute rehabilitation, family information needs include diagnosis, treatment, prognosis, treatment course, and cognitive and behavioral changes—all areas applicable to polytrauma caregivers. Given the constellation of injuries that patients with polytrauma sustain, polytrauma providers may be asked to provide a large volume of complex information to family caregivers. Research is needed to assess the specific information needs of caregivers in the face of such complexity. Several TBI studies have assessed the information needs of families during outpatient rehabilitation, community reentry, and community living; the same gaps likely exist for the polytrauma population. The gender differences in information needs observed by Ward among parents in a neonatal intensive care unit (in which fathers ranked their needs lower than mothers; Ward, 2001) and noted by polytrauma providers suggest gender may be an important polytrauma caregiver characteristic in addition to kinship, as suggested by Serio and colleagues (1995).

Key Practice Points

1. Polytraumas are injuries to multiple body systems or organs including traumatic brain injury (TBI), amputations, multiple fractures, burns, visual and hearing impairment and loss, pain, and posttraumatic stress disorder among other possible injuries.
2. Polytraumas appear to be more complex than treating simple TBI because of the constellation and severity of injuries.
3. Families of patients with polytraumatic injuries need support in caring for their loved one as well as help dealing with their own stress and anxiety.
4. Caregivers need a clear understanding of their loved one's physical and cognitive condition, the purpose of rehabilitation, and how the rehabilitation process facilitates recovery.
5. Providing clear, accurate, and comprehensive information in a sensitive and empathetic way is most effective for treating polytrauma patients.

No evidence-based guidelines appear to exist regarding the best time to communicate with polytrauma families after each phase of treatment and recovery. The three-time-periods approach proposed by Holland and Shigaki (1998) may incorporate a longitudinal fourth phase that includes information needs at several intervals postinjury. Interventions should be tested to assess optimal timing to communicate specific types of information in polytrauma caregiving populations (Holland & Holland, 2002; Holland & Shigaki).

Little research has been conducted on how to communicate with families of patients with TBI; consequently, the same gaps are present for polytrauma caregivers. The effectiveness of various formats and approaches (Holland & Shigaki, 1998; Morris, 2001) has not been tested (Gordon et al., 2006; Verhaeghe, Defloor, & Grypdonck, 2005). Clearly, TBI families often do not recall information that has been provided to them (Paterson et al., 2001), and this most likely is the case with polytrauma caregivers, especially given their level of emotion due to their loved ones' catastrophic injuries (Friedemann-Sánchez et al., 2008). Research on rehabilitation of other chronic neurological conditions provides possible solutions. Studies conducted during acute rehabilitation for stroke patients identify families' need to revisit information (Garrett & Cowdell, 2005; Wiles, Pain, Buckland, & McLellan, 1998) and suggest a spiral approach with increasing levels of complexity, which may help with understanding and retention (Garrett & Cowdell). Wiles and colleagues suggest providing individualized information available in a computerized system that can enable care

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staff to print the appropriate “packet” of information for each caregiver.

Intervention studies are almost entirely absent from the literature (Gordon et al., 2006). Scarce knowledge regarding types of information and timing and the approach for delivery that could most benefit families of patients with TBI exists. It is difficult to extrapolate extensively from this literature on the approaches that may benefit families of polytrauma survivors. One information-giving intervention study identified reduced distress among TBI caregivers during acute rehabilitation (Morris, 2001). A study of caregivers of critically ill patients conducted 2 days after admission into an intensive care unit had similar findings and suggests structured education programs have positive effects (Chiu et al., 2004).

Conclusions

Although TBIs are common among patients with polytrauma, these patients and their caregivers comprise distinct populations based in part on the constellation and severity of injuries that patients with polytrauma sustain and on the multiple and complex healthcare systems patients and caregivers must navigate (i.e., military treatment facilities, the VA, the community). Polytrauma rehabilitation providers need more information on what families need to know, ways to deliver the information, and when to deliver it. Providing information to families is important for quality care as veterans traverse several healthcare systems. Priorities for future research and intervention studies on polytrauma include understanding information needs during subacute, acute, and outpatient rehabilitation for polytrauma, as well as several years postinjury according to injury severity; assessing the extent of variation in information needs across these various time points; identifying the critical time periods at which information is most needed; identifying effective approaches to communicating information; and identifying whether and how families benefit in the long term from information received at specific time points. In particular, given the medical and administrative complexities that caregivers of polytrauma patients navigate, research on postdischarge needs is paramount. Research also can compare the needs of caregivers of patients with polytrauma returning from the current war to the needs of caregivers of patients injured by blasts in terrorist attacks in a civilian context.

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