Family Caregiver Education in Acute Therapies

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Abstract

This study examines the efficacy of a simple brochure in addressing the information needs of family caregivers of patients in acute settings. It was found that few (10% to 20%) of the encountered family members (N = 15) were *new* to caregiving required for their patients, with only some of these novices (67%) feeling ready to receive caregiver information in the first meeting with the clinician. Some of those “ready” individuals initiated searches on their own in the absence of the brochure, while others of them who *were* given the brochure did not read it. Some people only took the brochure “for later,” but ended up reading it. People who did not take advantage of the brochure when it was offered still expressed feeling better supported if not better informed. In sum, this literature-based intervention was efficacious: novice family caregivers ran a lower risk of remaining uninformed in an acute therapies setting when the clinician offered to provide information with a simple brochure.

Family Caregiver Education in Acute Therapies

Family members of individuals who have suffered brain damage experience significant stress (Jacobs, 1988; Lezak, 1978, 1988; Mauss-Clum & Ryan, 1981), where this stress is composed of such diverse influences as: 1) changes in life roles with the assumption of a ponderous caregiver burden (compounded with the resulting social isolation); 2) mourning the loss (in essence) of a loved one in the face of familial adjustments to drastic personality changes; and 3) intense feelings of frustration over a turbulent inability to control typical daily plans (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 1994; Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Corrigan, Whiteneck, & Mellick, 2004). It is not surprising that *information* and *support* top a caregiver's list of greatest needs; however, SLPs who adopt a dynamic systems (or ecological) model of therapy must be aware that these needs are generally reported by those caregivers to remain *unmet*, even years after the initial crisis has passed (Williams & Kay, 1991; Serio, Kreutzer, & Witol, 1997).

Over time, the unrelenting weight of chronic stressors can have a negative impact on a caregiver's perception of the person in their care, which is critical because a person receiving care is as strongly affected by the treatment that they receive from their family as they are by the original trauma (Ponsford, Sloan, & Snow, 1996). Uncontrolled studies and non-randomized group comparisons suggest that in *some* cases, even limited support (e.g. periodic telephone contact, a relatively brief peer mentoring program) can help to reduce caregiver burden enough to mitigate some of these negative effects (Brown et al., 1999; Man, 1999; Albert, Im, Brenner, Smith, & Waxman, 2002; Hauber & Jones, 2002; Hibbard et al., 2002). While there is anecdotal evidence in favor of the generic efficacy of longer-term support groups (Ostwald, Hepburn, & Burns, 2003) and family systems therapy (Maitz, 1991; Maitz & Sachs, 1995; Larøi, 2003), more rigorous research suggests that caregiver distress decreased coincident with family therapy, and while some pre-existing issues improved at first (e.g. marital relationship stress), the issues and anger returned two years after the therapy started (Perelsz & O'Loughlin, 1998). The question, then, is what type of intervention would have the most potent efficacy?

Education and behavior management in a support group appear to have a more pronounced effect than group education alone (Singer et al., 1994); however, in another study that was nearly as rigorous (Carnevale, Anselmi, Busichio, & Millis, 2002), no change in burden resulted from community-based programs whether or not their educational component was accompanied by behavior management. Crucially, whenever family support *did* help to moderate anxiety and depression, a caregiver's irritation or anger was tied most strongly to the degree of control they could exert over family life, such as in influencing changes in plans; therefore, Carnevale et al. suggested that it is meaningless to measure "burden" as if it were a homogenous, holistic unit, which is a contention consistent with results found in other research (Kowalsky-Hayner et al., 2001; Wells, Dywan, & Dumas, 2005; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). In light of these findings, Carnevale et al. recommended that intervention be tailored to fit each family, addressing those types of issues which were most amenable to change, such *as* control over daily plans.

Kreutzer et al. (2002) took these issues into account, providing an excellent contemporary resource for the design and implementation of a structured program with family education and caregiver support; however, consistent with the aforementioned research, it relied on longer-term interactions, generally on the order of a dozen meetings spread out over months or years, which is a luxury that acute therapies cannot afford. Just as clearly, the issue cannot simply be avoided by telling families to *wait* for support until they enter the extended care phase of the crisis.

Intriguing questions arise, then, when projecting these extended-care research findings onto an acute therapies setting, such as: 1) how does the SLP know – without being intrusive – when the family is *ready* for information; 2) what might the family want to know; 3) what is the family's preferred learning style (e.g. lecture vs. literature); and 4) how does this all vary with the specific medical event and symptoms that the family is facing (e.g. cognitive impairment versus dysphagia).

To address these questions, the current study reviews what little research exists on the topic of family caregiver education in an acute therapies setting, deriving principles for use in cases where a *new* need for caregiving has arisen as a consequence of a previously independent family member suffering acute, recent brain damage. The answers to the following "cascaded" research questions are of particular interest in gauging the efficacy of such an acute therapies intervention:

- Of all of the family members who are seen in an acute therapies context, how many (i.e. what percentage) are likely to be *novice* caregivers (i.e. likely to be in relatively greater need of information)?
- Of those novice caregivers, how many are likely to express a desire for information at the acute therapies stage (i.e. earlier instead of later, or perhaps never)?
- Of those who are given opportunities to receive information (or not), how many will actually *pursue* those opportunities during that acute stage?
- Of those who *don't* pursue those opportunities (i.e. who don't read the literature), how many will still report a perceived benefit (e.g. feeling better supported)?
- Of those who *do* pursue those opportunities (i.e. who actually read the literature), how many will report a perceived benefit (i.e. feeling better informed or supported)?

In very broad terms, this study found that about 10% of encountered family members – people who were *already* under considerable stress – ran a significant risk of feeling unsupported; that is to say, they were novice caregivers who expressed a desire for information sooner rather than later. That stress potential was reduced *easily*, *adequately*, and *unobtrusively* by giving family members a simple brochure containing the following information: 1) three cardinal principles of self-care for family caregivers; and 2) a list of resources addressing family caregiving issues and the specific health conditions that had necessitated such care. A literature-based intervention for family caregiving education was not needed often, but when it was, it was efficacious; crucially, the benefit in stress reduction far outweighed the cost of implementation.

Literature Search

In searching on any topic involving language and cognition, there are two databases that should always be consulted: MEDLINE and PsycINFO. When the terms "family," "education," and "program" were pursued as keyword combinations (i.e. appearing in the same abstract, but not necessarily near each other), the returned results were too numerous to be reviewed for this project of limited scope; therefore, the keywords were searched as a whole phrase:

	Results per Database	
	MEDLINE	**PsycINFO**
family and education	43463	9804
family and education and program	8096	1559
"family education"	473	353
"family education" (and program)	116	80
"family education program" (but not donor)	10[1]	9[2]

Table 1: Literature Search Results

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[1] Three additional articles were disallowed as off topic.

[2] Three additional articles were off topic, and one was just an erratum notification.

To further refine the topic of the retrieved articles, an additional keyword (i.e. “brain,” “aphasia,” or “literature”) was combined with the phrasal searches; however, this winnowing produced no articles at all; in contrast, *dis*allowing the term “donor” removed four of the outliers (regarding education about organ donation) without blocking any of the relevant studies. As all 10 of the MEDLINE articles were published within the last 20 years, the PsycINFO search was conducted on the 1985-present database. Ignoring four cases of MEDLINE overlap, that search returned nine relevant articles, bringing the total number of unique articles to 19.[3]

All of these articles were read in full to identify appropriate research in general, and to select in specific only those studies whose education programs were both data based and adaptable to an acute therapies setting. Applying these two criteria resulted in discarding 17 of the 19 articles (89%). Of the two remaining articles (11%), only one studied family education specifically in regard to brain injury (Smith & Testani-Dufour, 2002); however, the other article was retained for its insight into a family education program that appealed to a significant literature base (Bartholomew et al., 1997). One further article was added to the review set as a result of scanning the contents of *Brain Injury* (Morris, 2001), but no germane material was found in similarly searching the *Journal of Head Trauma Rehabilitation*.[4] The identified literature set, then, consisted solely of these three articles, and their analysis provided the design basis for the intervention implemented in this study.

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[3] A search on ERIC (for the sake of thoroughness) revealed 28 articles, but they were all about educating families of school-aged children (e.g. teen pregnancy, the evils of television, and so on); in that sense, the use of MEDLINE rather than ERIC functioned as a “medical” versus “school” keyword filter, which focused the articles on families whose needs went beyond those met by academic lectures.

[4] The results of those searches fed much of the introduction that appears in this study, addressing as it did the efficacy of general family systems therapy and education as it applied in cases of brain injury.

Literature Analysis

The three articles identified by the literature search were analyzed to reveal trends in: 1) the characteristics of the participant sets; 2) the relative efficacy of the intervention components; and 3) the level of methodological rigor[5] supporting 4) the research outcomes of the studies:

	Morris **2001**	**Smith & Testani-Dufour** **2002**	**Bartholomew et al.** **1997**
Participants	**Caregivers** (N = 33; age 16-65; live w/family member w/TBI > 1 mo. post-injury; *no* prev. BI; *no* hx subs. abuse). [GCS[6] 3-14 at admit]	**Caregivers** (N = 28; convenience sample; 11 spouses; 14 parents; 3 siblings). [fam. member w/TBI: FIM < 39 at admit]	**Parents** (N = 199): 15m, 184 f; age 21-63. [child w/cystic fibrosis: age <1 to 18]
Intervention	**1st appointment**: A) 3 questionnaires (GHQ, HADS, and "objective burden" Symptom Checklist); B) P receives information booklet on BI (pathophysiology; changes in emotion, cognition, behavior; self care). **Phone** (+*1 wk*): A) answer Qs; B) set up 2nd appt. **2nd appointment** (+*3-4 wks*): A) answer Qs; B) 3 questionnaires; C) in-house Booklet Questionnaire.	**Within 72 hrs of admission**: A) assess family learning and readiness profile (incl. literacy, culture, and other barriers and preferences); B) P choses: start education immed. or delay by a week. **When P indicated readiness**: A) TBI manual; B) lecture series (pathophysiology, seizures, family issues, behavioral and memory changes). **1-2 wks before discharge**: A) 1:1 hands-on (e.g. safe transfers)	**On enrollment**: A) pretest: cognitive (e.g. self-efficacy, CF knowledge, outcome expectations); behavioral (e.g. problem solving); quality of life (e.g. IFS, PSI, QWBS); B) CF center subgroup begins *self-paced print curriculum* (with sig. hands-on components); Primary topics: coping; respiration; nutrition and malabsorption; communication. **Posttest** (~*2 years later*): A) same as pretest set

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[5] The American Speech-Language-Hearing Association (ASHA) supports evidence-based practices in general (www.asha.org/members/ebp/default), and in specific the levels-of-evidence hierarchies discussed on the websites for the Agency for Healthcare Research and Quality (www.ahrq.gov/clinic/epcsums/strengthsum.htm) and the Oxford Centre for Evidence-Based Medicine (www.cebm.net/levels_of_evidence.asp). The Oxford rating system is the one used in this study.

[6] Sources for all tests, scales, and measures and listed in Appendix A.

Methods	**Level 3b+**: longitudinal, mixed variable, within- and between-subject, no control group	**Level 5b+**: qualitative; w/in-P; semi-structured, open-ended interview with P; phenomenological analysis	**Level 2b-**: pretest-posttest nonequivalent comparison group
Outcome	**1**: No *statistically significant* drop in anxiety for either subgroup, but downward *trend* apparent. **2**: Ps tend to report some increase in feeling able to carry out tasks. **3**: Greater decrease with 'early' subgroup, but no ability to say *which* info caused this effect. **4**: Preferred time to receive booklet: 56% = at discharge; 30% = in hospital; 7% = 3+ months; 7% = no response.	**1**: 'Pen and paper' profiling too stressful for Ps, discontinued in favor of interview. **2**: Ps display diversity in learning-style preferences. **3**: Some Ps want info & training immediately (anxious *without* it), but many prefer to wait at least a week (anxious *with* it). **4**: Keep comm. simple and respectful, listen first. **5**: Peer support includes only those Ps whose family members are at similar stages of recovery.	**1**: Caregivers increase knowledge of CF care, self-efficacy, self-management, and 3 of 4 aspects of problem solving (i.e. concrete and emotional appraisal, plus means, not alternatives). **2**: Caregivers with initial lower confidence in CF management show improved confidence. **3**: Caregivers show no change on parenting stress, family impact, outcome expectations, or assessments of the child's quality of well-being.

Table 2: Literature Analysis Table

Broadly, this literature set determined that direct educational intervention tended to have a positive impact on a family member's perceived need for support and information; for example, participants in education programs tended to report qualitative improvements in feelings of capability and depression/anxiety (Bartholomew et al., 1997; Morris, 2001). This impact appeared to be greater the earlier the education was received, at least in part because the perceived need for information dropped as family members gained practical experience with caregiving (Morris, 2001). It is important to note, however, that blanket early intervention did *not* appear to be an appropriate extrapolation of this finding, because the literature also contended that some people were not ready for – and in some cases expressly did not want – information to be given to them too early (Smith & Testani-Dufour, 2002).

Caregiving is a sensitive issue; some people are simply not ready to be approached *at all*, particularly in the earlier therapy settings. Bartholomew et al. (1997) indicated that family members often don't think of themselves *as* caregivers, *even if* they have been caregivers in actual fact for several years. For such people, the topic of caregiving is essentially a novel prospect, profiling the patient's dependence. In the acute setting in particular, that profile is susceptible to being misinterpreted as a prognosis; in other words, family members are often still waiting to see how their loved one will stabilize at that point, and a discussion of caregiving – however speculative in intent – runs the risk of causing them unnecessary additional distress, suggesting to them that the patient *will* (rather than *might*) not be able to be independent. The intervention script used in this study was therefore designed to take into account the need to be sensitive to the participant's readiness to broach the subject of caregiving in the first place, much less in any sort of depth.

Balanced against this need for caution, the literature made it clear that simply avoiding the topic altogether would not serve all caregivers equally well, because some people *did* want information early (and in some cases immediately). The literature further found that this need was met by the availability of a planned program of education. Among such "information-ready" people there were found further variations in preferences for receiving that information through discussion, literature, or both. The research indicated that these readiness and learning style preferences were *not* best gauged with "pen and paper" surveys, as participants judged that process to be too stressful. There's no time in an acute setting for that kind of approach anyway. A casual interview should suffice, where the literature suggested the following guidelines: listen first, keep the approach respectful, and keep the information simple. The current intervention was designed with those principles in mind.

Finally, given the education programs described in the articles, it was determined that a literature-based approach would fare better than one that was dependent on dialogue or lecture: while either dialogue or literature could be tailored given family's *learning style*, a literature-based program would be more easily tailored to a given family member's *readiness*; in other words, literature could be easily read, saved, or tossed as best fit an individual caregiver's preference. The text of the brochure used in this study has been captured in Appendix B.

Participants

Candidates for participation were all family members of patients who were receiving therapy for *acute* brain injury, whether primary (e.g. traumatic brain injury, brain attack, or brain tumor operation) or secondary (e.g. anoxia associated with a heart attack). Patients were being seen for "speech" (i.e. dysphagia), "cognition" (i.e. aphasia, dementia), or both. The criteria for participant selection were pragmatic in nature: 1) the candidate family member showed no evident signs of distress when the family caregiving topic was raised;[7] 2) the family member had no significant previous experience with, or knowledge of, family caregiving (such as the cardinal rules of self-care);[8] 3) the patient's injury would necessitate this family member's significant participation in caregiving; and 4) the family member visited the patient during at least two therapy sessions. The first criterion excluded candidates who might be at particular risk of emotional harm from the intervention. The next two criteria selected participants who were relatively more sensitive to the intervention effects. The last criterion resulted from excluding candidates who were not available for a post-intervention measure of change.

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[7] In 12 of 15 cases (80%), the candidate introduced the topic, and in 3 of 15 (20%), the patient did.

[8] To help ensure that previous experience with family caregiving was not significant, candidates were only selected as participants if the patient had been living independently of the caregiver (i.e. without any health care concerns great enough to warrant caregiving by *that* family member).

Due to constraints in the clinical setting, participant interviews could not be conducted to collect information about age and education; however, *incidental* conversations suggested that all participants ranged in age from late 20s to late 60s, and were literate to at least the middle school level. The clinic sample included the following *adults*: three spouses/partners, one parent, seven children, two children-in-law, one grandchild, and one sibling (as associated with 11 patients).

Each participant (P; N = 15) fell into one of two groups, based on how early in the study they were visited at the hospital: 1) a quasi-control group (CG) whose members *were not* given any caregiving literature during their visits with the clinician (N = 6); and 2) an intervention group (IG) whose members *were* given an information sheet on family caregiving during their first meeting of any significant length (N = 9; cf. Appendix B). The CGs were all seen during the first half of the study (i.e. while the literature was still being developed), and the IGs were all seen during the second five weeks (i.e. after the brochure had been cleared for distribution).

Implementation

The first research question was addressed during the selection process (i.e. the prevalence of novices among caregivers), leaving the first *visit* between clinician and caregiver to speak to the *second* question, namely diversity in readiness: “Of those novice caregivers, how many are likely to express a desire for information at the acute therapies stage?” At the first meeting where P had approached the topic of caregiving, the clinician asked, “Would you like information about family caregiving soon, or would you rather wait until later?” The assumption was that P would not ask for information unless P felt the need for it. P then stated their readiness with one of four types of responses: 1) some CGs wanted information soon (N = 4); 2) some CGs wanted it later (N = 2); 3) some IGs wanted it soon (N = 6); and 4) some IGs wanted it later (N = 3). For the sake of clarity, this distribution will be represented graphically as follows:

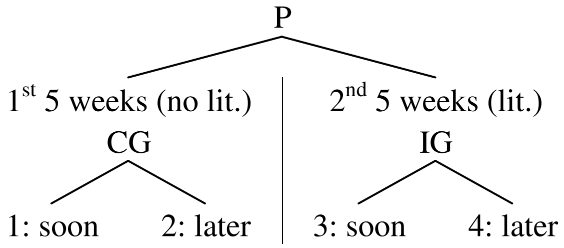

Figure 1: P's Stated Readiness for Information at the First Visit

The intervention script was designed to address each of those four stated preferences as follows:

1. CG wants info soon (*no* caregiver literature given at *any* meeting): "I can have more information available next time I see you. If I *don't* happen to see you again, then you can request it from a health care worker who follows your case."
2. CG wants info later (*no* caregiver literature given at *any* meeting): "A health care worker who follows your case can help you get information when you're ready for it."
3. IG wants info soon (caregiver brochure given at the *first* meeting): "Here is a brochure that covers the most important points about family caregiving, and lists other places where you can look for much more thorough information."
4. IG wants info later (caregiver brochure given at the *first* meeting): "Later on, when you're ready, you can refer to this brochure. It covers the most important points about family caregiving, and lists other places where you can look for much more thorough information."

P's response, then, would be taken to characterize their feeling of being uninformed, indicating a desire for information soon, later, or possibly never. CGs were not given any caregiver literature at that or any later meeting (during the study). The brochure given to the IGs (both "soon" and "later") at the first meeting contained the following information (cf. Appendix B):

- three important rules for family caregiver self-care (i.e. meet your personal needs, take breaks, and protect your mental and emotional health);
- links to three websites addressing family caregiving (Family Caregiving 101, National Family Caregivers Association, National Alliance for Caregiving); and
- links to the public domain of the ASHA speech web pages for information about the specific disorder that was driving the need for caregiving.

The researcher had developed the brochure in accordance with the principles derived from the literature analysis. After being given this brochure, IGs were asked if they would be comfortable with information about their opinion being shared with the clinician's colleagues, who were interested in planning better interventions. All IGs agreed to this sharing; in addition, all IGs reported being internet literate and having internet access, which was important because the resources listed for future reference in the family caregiver brochure were given as website links.

As P was expected to specify a level of feeling uninformed during the first visit (i.e. "soon" versus "later"), the second visit (using the third research question) was designed to find out if P now felt any better informed *compared* to that first visit. This was important whether or not P had received a brochure (i.e. CG versus IG), or had asked for information soon rather than later. The third research question portrayed this comparison as follows: "Of those Ps who are given opportunities to receive information (or not), how many will actually *pursue* those opportunities during that acute stage?" Comparing results among the four subgroups (cf. Figure 1, above) across these two time-separated visits (cf. Figure 2, below) would help to determine whether the brochure in specific might have been instrumental in effecting any change in P's perceived feeling of being uninformed. Of course, the intervention for CGs and IGs during this second visit would need to diverge somewhat, because CGs had not been given any literature.

During the second *CG* visit, then, all CGs (both “soon” and “later”) were asked, “Did you happen to come across any information on family caregiving since our last visit?” (IGs would be asked this same question.) That ambiguity left CG open to mention deliberate and/or accidental exposure (a positive response), or to report feeling no change in being informed (a negative response). Of particular interest here was any variation in type among positive responses, such as passive exposure to information from other sources (e.g. friends, social workers), as opposed to an independent initiative to actively find information; furthermore, if CG did initiate a search, it was important to know whether or not they were successful. Primarily, it was important to know whether CGs in the “soon” and “later” subgroups would report different amounts of change.

With this, CGs completed their participation in the study. As per their wish, no further information was given to CGs in the “later” subgroup; in contrast, because they had requested information in the first visit, CGs in the “soon” subgroup were briefed on the need for family caregiver self-care, and were given information sheets addressing specific disorders (e.g. dysphagia, aphasia). Those sheets had long been used in the hospital’s acute therapies setting prior to the current clinician’s arrival, were derived from material available to the public on the ASHA website (www.asha.org/public/speech), and had been approved by the researcher’s supervisor for distribution to patients and their family members. This briefing neither withheld treatment from the CGs (where further help would also be available soon from healthcare workers following the case), nor did it require distributing the brochure that was to be used with the IGs, as that document would not be fully developed or approved for use until the latter five weeks of the study.

During the second *IG* visit, members of both the “soon” and “later” subgroups were asked the same question that had been used with the CGs, namely, “Did you happen to come across any information on family caregiving since our last visit?" In addition to the responses that had been of interest with the CGs, it was important to know whether the IGs (in both the "soon" and "later" subgroups) would suggest that the *brochure* in particular had contributed to any changes in their reported perceptions about feeling informed; in other words, the IG context allowed for answers about reading the brochure (i.e. a positive response) or not (i.e. a negative response), or about any further active searching based on that information. If IG reported feeling better informed as a result of reading the brochure, the clinician would confirm this assertion by eliciting information in conversation about family caregiver self-care, which was a prominent part of the brochure. This completed the IG intervention.

In sum, then, this study sifted all Ps into one of eight response categories, based first on their point of introduction into the study (i.e. the CGs entered during the first 5 weeks, and the IGs during the latter five), and then on subsequent divisions according to two successive binary choices (i.e. "soon" versus "later" polled at the first visit, and then "positive" versus "negative" polled at the second):

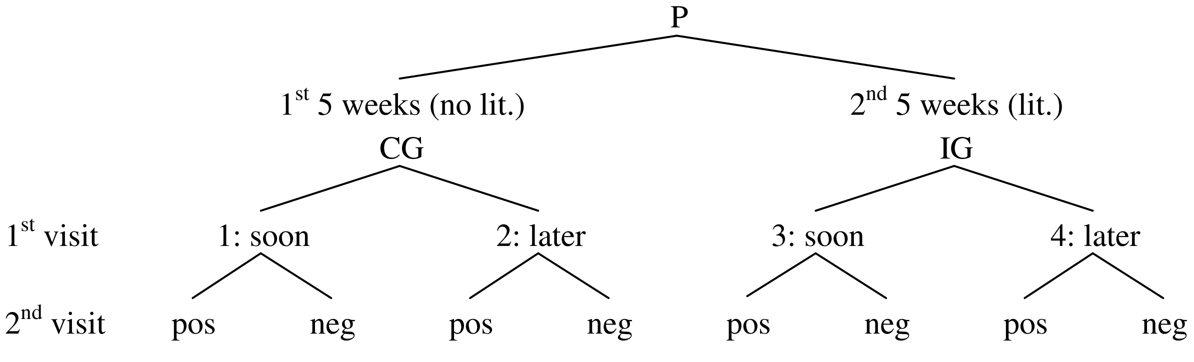

Figure 2: P's Stated Feeling of Being Informed at Second Visit

It was anticipated that the distribution of Ps among these response categories, and the elaboration of those responses by those Ps at their second visit, would inform a viable assessment of the effectiveness of this particular literature-based intervention in an acute therapies setting.

Results

At the end of the study, the actual distribution of Ps among response categories was as follows (diagrammed here to clarify discussion):

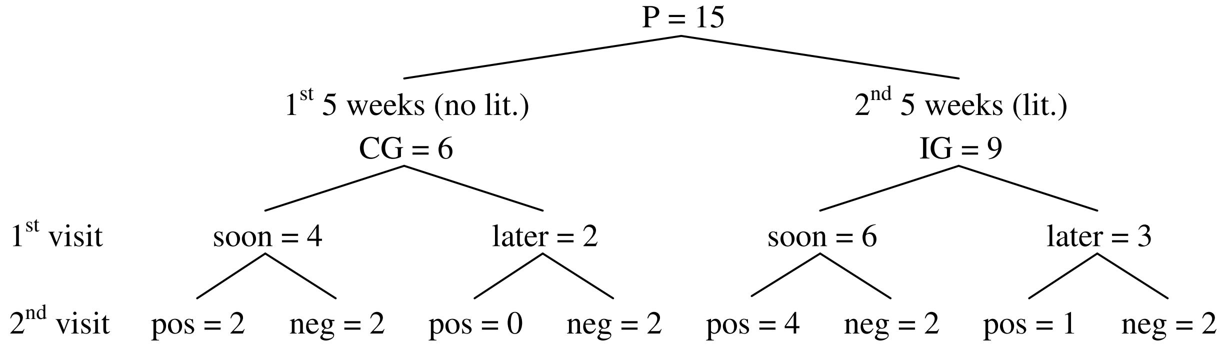

Figure 3: P's Stated Feeling of Being Informed at Second Visit

The five research questions align with successively lower lines in this figure.

To begin at the top, then (P = 15), the selection process itself addressed the first research question: "Of all of the family members who are seen in an acute therapies context, how many (i.e. what percentage) are likely to be *novice* caregivers (i.e. likely to be in relatively greater need of information)?" By far, most of the patients seen in the acute care setting are already receiving (or have received) some form of caregiving, and so *truly* novice family caregivers are fairly rare. A rough estimate lies between 10% and 20%, perhaps less, with the actual figure being difficult to pin down with precision in this study because of false negatives and positives who were difficult to identify more specifically due to the lack of more extensive interviews.

The first visit then addressed the second research question, namely: "Of those novice caregivers, how many are likely to express a desire for information at the acute therapies stage (i.e. earlier instead of later, or perhaps never)?" At the first visit, none of the Ps outright denied the need for information, and the stated readiness for information was (as might be expected) the same for both subgroups: 67% of CGs (4/6) asked for information soon, as did 67% of IGs (6/9).

The second visit was designed to find out how P's feelings about being informed had changed since the first visit, and whether any such change could plausibly be attributed to the literature-based intervention; in that sense, the second visit addressed all three of the remaining research questions for both the CG and IG subgroups, starting with: "Of those who are given opportunities to receive information (or not), how many will actually pursue those opportunities during that acute stage?" Although none of the CGs (either "soon" or "later") had been given such an opportunity (i.e. any literature) at the first visit, 50% of the "soon" CGs (2/4) indicated that they had been exposed to information about family caregiving *anyway* since the first visit. None of that exposure was "passive," as both of those individuals had initiated internet searches on their own. As it happened, those searches both led to some of the same sites that were listed in the family caregiver brochure. None of the "later" CGs (0/2) reported any "positive" interim exposure to information on family caregiving, passive or otherwise.

The final two research questions addressed only the IGs at their second visit, as they were the only Ps given the family caregiving brochure, and so were the only ones in a position to "pursue those opportunities" to become better informed. The penultimate research question was, therefore, posed as follows: "Of those who *don't* pursue those opportunities (i.e. who don't read the literature), how many will still report a perceived benefit (e.g. feeling better supported)?" In this study, 67% of the "later" IGs (2/3) did *not* read the brochure before the second visit, and, like the "later" CGs, they reported no other exposure to information about family caregiving. (The one remaining "later" IG did read the brochure, and that person is discussed below.) Of the "soon" IGs, 33% (2/6) did *not* read the brochure in the interim, reported no other exposure, and reported no change in feelings of being informed; however, both of these IGs still indicated that they appreciated the support, and would read the information later.

The ultimate research question was: “Of those who *do* pursue those opportunities (i.e. who actually read the literature), how many will report a perceived benefit (i.e. feeling better informed or supported)?” Despite being in the “later” subgroup, one IG (1/3) read the brochure “because it was there anyway,” reported feeling better informed, and was able to discuss family caregiver self-care. The remaining 67% (4/6) of the “soon” IGs reported feeling better informed after having read the brochure, and went on to talk cogently, if briefly, about family caregiver self-care material in that brochure; furthermore, 50% (2/4) of those informed IGs had actually followed the internet links, and talked about information found there.

These results suggest that the brochure provided an unobtrusive, emotionally low-impact vector for getting the right amount and type of information to the right people at the right rate. To begin with, distributing the brochure did no harm to the people who received it, even when they did not initially feel ready to read it soon; furthermore, it would have proven helpful to those people who initiated their own searches in its absence, as it linked to the same information that they had to spend time finding on their own. People who asked for information reported that the brochure told them what they needed to know. Even the people who *didn’t* read the brochure still reported feeling better supported during their time of crisis just from having received it. Given that information and support were the two specific, chronically unmet needs that the brochure was designed to meet, the intervention was an unqualified success.

Conclusion

The results of this study were found to be consistent with general principles derived from the existing literature. Interventions should be developed from an ecological perspective that encompasses the family members (Bartholomew et al., 1997), balancing a patient’s need to have their caregiver be educated against that same caregiver’s readiness to *be* educated, while further respecting their preferred learning style (Smith & Testani-Dufour, 2002). Research also suggests that even though a literature-based approach is relatively insensitive to diversity in learning style preference (i.e. some people do not like to learn through literature), it compensates for this flaw with its relative sensitivity to readiness (i.e. whether or not people like literature, they appreciate being able to access it or not as they are ready) (Morris, 2001; Smith & Testani-Dufour, 2002). This sensitivity to readiness is additionally important because earlier exposure to information tends to be associated with a better quality of life (Morris, 2001). Finally, while the current study confirmed that the intervention led to caregivers reporting that they felt better informed and supported, it was not possible to test this change in as extensive and objective a manner as the existing research (Bartholomew et al., 1997).

Estimates based on the caregiver responses drawn from this study also support the validity of the following general conclusions which, when taken together, portray a likely efficacy scenario for a literature-based intervention for family caregiving education in an acute therapies setting:

- At least *some* of the family members encountered in an acute therapies context are likely to be *novice* caregivers; that is to say, they will feel relatively uninformed on the topic of caring for a family member with an acute brain injury.
- *None* of these novices can reasonably expect to receive any *passive* exposure to family caregiver information during the acute phase of care.
- *Most* such novices will feel ready for information as early as the first meeting with the clinician.
- In the absence of any educational intervention, *some* such ready novices will initiate successful searches on their own before their next meeting with the clinician.

- *Most* such ready novices will take advantage of literature if it is offered, with the remainder feeling better supported even if they are not better informed.
- Even novices who initially report *not* feeling ready will sometimes take advantage of literature soon if it is made available for them to read when they are ready.

In sum, this literature-based intervention is efficacious. While it is unknown whether caregiving skills actually change, novices run a lower risk of feeling uninformed when the clinician offers information in the form of a simple brochure. Given that this brochure *unobtrusively* addresses the need to *feel* informed, intervention is likely to lead to lower caregiver stress, which is likely to lead in turn to lower health risks for both the caregiver *and* the patient, suggesting that this intervention would be effective as well.

When it comes to issues left for future research, a simple list of holes to plug will not suffice; for example, while the sample size appears small, it was adequate for a case application paradigm adapted to an acute therapies setting, achieving richness along a population dimension (i.e. more people were seen for a shorter time apiece over 10 weeks) when a temporal one was impractical (i.e. one person might normally be seen for the whole 10 weeks). That said, only a small fraction of the family members needed intervention, and future researchers should plan for *more time* to reach a larger population (e.g. perhaps a year to encounter 100 qualifying novices).

Similarly, issues of generalization and maintenance could not be addressed practically under the current constraints, but future research could plan to follow family caregivers through rehabilitation and into the home setting at intervals over time, to help determine whether early educational intervention had any lasting effect, particularly given that real-world intervention might normally have been instantiated *after* the acute stage, during rehabilitation and so on. The number of *possible* educational paths that a family member could follow across that time is staggering (including the path of *no* education), making the eight paths followed in the current study look rather pale. Similarly, future studies could address any finer-grade effects associated with the caregiver's relationship to the patient (i.e. spouse, child, in-law, and so on).

One outstanding issue is *not* affected by these limitations of adaptation and setting, and that is effectiveness. The current study cannot make strong statements about which *parts* of the brochure might have helped to reduce feelings of being uninformed. That could be addressed in a similar adaptation of a case application paradigm, or in more rigorously controlled research. The whole point of this study, however, was to pilot a method for satisfying the information needs of a learning- and readiness-diverse population in a therapy setting which inherently limited the accurate gauging of such preferences. Given these constraints, common sense dictates that as long as one person found at least one part of the family caregiving brochure to be helpful, and no one found it to be harmful, then the whole document as is stands was worth piloting.

Backing out to take a bird's eye view, the current study can be seen to exist in a research space defined by fields of study that are either in their infancy or are just hitting their stride, as follows: 1) patients and other family members exist within families as systems; 2) therapists and those families are partners in even larger-scale caregiving systems; and 3) therapists (as opposed to therapy itself, ultimately) must be sensitive to diversity in both readiness and learning styles within those caregiving systems. The sensitivity and specificity of this intervention, for example, would benefit from future research into an interview method that would allow readiness and learning style to be assessed *without* increasing family stress in the acute setting. More to the point, *any* future research that explores the breadths and depths of this vast new space will further inform the intervention proposed here, as it was *based on* principles drawn from the literature pioneering this field.

References

Albert, S. M., Im, A., Brenner, L., Smith, M., Waxman, R. (2002). Effect of a social work liaison program on family caregivers to people with brain injury. *Journal of Head Trauma Rehabilitation*, *17*(2), 175-189.

Bartholomew, L. K., Czyzewski, D. I., Parcel, G. S., Swank, P. R., Sockrider, M. M., & Mariotto, M. J. (1997). Self-management of cystic fibrosis: short-term outcomes of the Cystic Fibrosis Family Education Program. *Health Education & Behavior*, *24*(5), 652-666.

Brown, R., Pain, K., Berwald, C. Hirischi, P., Delehanty, R., & Miller, R. (1999). Distance education and caregiver support groups: comparison of traditional and telephone groups. *Journal of Head Trauma Rehabilitation*, *14*(3), 257-268.

Carnevale, G. J., Anselmi, V., Busichio, K., & Millis, S. R. (2002). Changes in ratings of caregiver burden following a community-based behavior management program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *17*(2), 83-95.

Corrigan, J. D., Whiteneck, G., & Mellick, D. (2004). Perceived needs following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *19*(3), 205-216.

Jacobs, H. (1988). The Los Angeles Head Injury Survey: procedures and initial findings. *Archives of Physical Medicine and Rehabilitation*, *69*(6), 425-431.

Hauber, R. P., & Jones, M. L. (2002). Telerehabilitation support for families at home caring for individuals in prolonged states of reduced consciousness. *Journal of Head Trauma Rehabilitation*, *17*(6), 535-541.

Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., et al. (2002). *Journal of Head Trauma Rehabilitation*, *17*(2), 112-131.

Kolakowsky-Hayner, S. A., Miner, K. D., Kreutzer, J. S. (2001). Longterm life quality and family needs after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *16*(4), 374–385.

Kreutzer, J. S., Kolakowsky-Hayner, S. A., Demm, S. R., & Meade, M. A. (2002). A structured approach to family intervention after brain injury. *Journal of Head Trauma Rehabilitation*, *17*(4), 349-367.

Kreutzer, J. S., Serio, C. D., & Berquist, S. (1994). Family needs after brain injury: A quantitative analysis. *Journal of Head Trauma Rehabilitation*, *9*(3), 104-115.

Larøi, F. (2003). The family systems approach to treating families of persons with brain injury: a potential collaboration between family therapist and brain injury professional. *Brain Injury*, *17*(2), 175-187.

Lezak, M. (1978). Living with the characterologically altered brain injured patient. *Journal of Clinical Psychiatry*, *39*(7), 592-8.

Lezak, M. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology*, *10*(1), 111-123.

Maitz, E. (1991). Family systems therapy applied to head injury. In J. M. Williams & T. Kay (Eds.), *Head Injury: A family matter* (pp. 65-79). Baltimore, MD: Paul H. Brookes Publishing Co.

Maitz, E., & Sachs, P. R. (1995). Treating families of individuals with traumatic brain injury from a family systems perspective. *Journal of Head Trauma Rehabilitation*, *10*(2), 1-11.

Man, D. (1999). Community-based empowerment programme for families with a brain injured survivor: an outcome study. *Brain Injury*, *13*(6), 433-445.

Mauss-Clum, N., & Ryan, M. (1981). Brain injury and the family. *Journal of Neurosurgery Nursing*, *13*(4), 165-169.

Morris, K. C. (2001). Psychological distress in carers of head injured individuals: the provision of written information. *Brain Injury*, *15*(3), 239-254.

Ostwald, S. K., Hepburn, K. W., & Burns, T. (2003). Training family caregivers of patients with dementia. *Journal of Gerontological Nursing*, *29*(1), 37-44.

Perelsz, A., & O'Loughlin, M. (1998). Changes in stress and burden in families seeking therapy following traumatic brain injury: a follow-up study. *International Journal of Rehabilitation Research*, *21*(4), 339-354.

Ponsford, J., Sloan, S., & Snow, P. (1995). *Traumatic brain injury: Rehabilitation for everyday adaptive living*. Hove, UK: Lawrence Erlbaum Associates, Publishers.

Serio, C. D., Kreutzer, J. S., & Witol, A. D. (1997). Family needs after traumatic brain injury: a factor analytic study of the Family Needs Questionnaire. *Brain Injury*, 11(1): 1-9.

Singer, G. H. S., Glang, A., Nixon, C., Cooley, E., Kerns, K. A., & Williams, D. (1994). A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. *Journal of Head Trauma Rehabilitation*, *99*(4), 38-49.

Smith, M. S., & Testani-Dufour, L. (2002). Who's teaching whom? A study of family education in brain injury. *Rehabilitation Nursing*, *27*(6), 209-14.

Tooth, L., McKenna, A., Barnett, A., Prescott, C., & Murphy, S. (2005). Caregiver burden, time spent caring and health status in the first 12 months following stroke. *Brain Injury*, *19*(12), 963-974.

Toprac, M. G., Rush, A. J., Conner, T. M., Crismon, M. L., Dees, M., & Hopkins, C. (2000). The Texas Medication Algorithm Project: *Journal of Clinical Psychiatry*, *61*(7), 477-486.

Wells, R., Dywan, J., & Dumas, J. (2005). Life satisfaction and distress in family caregivers as related to specific behvioural changes after traumatic brain injury. *Brain Injury*, *19*(13), 1105-1115.

Williams, J. M., & Kay, T. (1991). *Head Injury: A family matter*. Baltimore, MD: Paul H. Brookes Publishing Co.

Appendix A: Sources for Tests, Scales, and Measures

Functional Independence Measure (FIM): Hamilton, B. B., Granger, C. V., Sherwin, F. S., Zielezny, M., & Tashman, J. S. (1897). A uniform national data system for medical rehabilitation. In Fuhrer, M. (Ed.) *Rehabilitation outcomes: analysis and measurement* (pp. 137-147). Baltimore, MD: Paul H. Brookes Publishing Co.

General Health Questionnaire (GHQ): Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the general health questionnaire. *Psychological Medicine*, *9*, 139-145.

Glasgow Coma Scale (GCS): Teasdale, G. M., & Jennett, B. (1976). Assessment and prognosis of coma after head injury. *Acta Neurochirurgica*, *34*(1-4), 45-55. See also, Teasdale, G. M., Jennett, B., Murray, L., & Murray, G. (1983). Glasgow coma scale: To sum or not to sum. *Lancet*, *2*(8351), 678.

Hospital Anxiety and Depression Scale (HADS): Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Scandinavica*, *67*, 361-370.

Impact on Family Scale (IFS): Stein, E. K. R., & Reissman, C. K. (1980). Development of an impact-on-family scale: Preliminary findings. *Medical Care*, *18*(4), 465-472.

Parenting Stress Index (PSI): Abidin, R. R. (1983). *Parenting Stress Index Manual*. Charlottesville, PA: Pediatric Psychology Press.

Quality of Well-Being Scale (QWBS): Bush, J. W. (1981). *Quality of Well-Being Scale: Function Status Profile and Symptom/Problem Complex Questionnaire*. Health Policy Project, San Diego, CA: University of California.

Symptom Checklist: McKinlay, W., Brooks, N., & Hickox, A. (1990). *Questionnaire for Relatives/Post Head Injury Progress Assessment*. Authors and Case Management Services, Ltd.

Appendix B: Family Caregiving Information Brochure

The following material is the text of the single-sheet, two-sided brochure that constituted the distributed literature in the intervention. Many of the family caregivers were vision impaired, so the text was 1.5 spaced, with headers centered in 24 point bold font, and the body in 18 point. An effort was made to keep the register accessible to a middle school level of literacy.

Family Caregiving

It's natural for your attention to be focused on the needs of your family at this time… that's just part of your role as a family caregiver. Another part of that role will be to remember to take care of *yourself* so you don't burn out. When you are ready for more information, this document is likely to be useful to you.

Family Caregiving 101 (www.familycaregiving101.org) is a great place for new caregivers to start looking for ideas and advice.

The **National Family Caregivers Association** (www.nfcacares.org) "was created to educate, support, empower, and speak up for America's family caregivers so that all caregiving families can have a better quality of life." This site has a personal feel to it, and provides a strong sense of community. There are guides covering topics such as care coordination, patient safety, and financial management, including tax tips and Medicare benefits. Their quarterly newsletter, *Take Care!*, is free.

The **National Alliance for Caregiving** (www.caregiving.org) has a more formal tone, gathering input from organizations rather than people. There is a great deal of valuable information here on research and policy development, but as a family caregiver you might be most interested in their free brochure: *Care for the Family Caregiver: A Place to Start* (www.caregiving.org/pubs/brochures/CFC.pdf)

The **American Speech-Language-Hearing Association** website (www.asha.org/public/speech) provides more detailed information about specific types of disorders of speech, language, hearing, cognition, and swallowing, as well as their typical effects on a family.

Self Care

You can’t take care of anyone else if you wear yourself out; that’s just common sense. The following steps are all vital parts of family caregiving:

- Meet your personal needs: sleep, eat, exercise, and maintain your contacts with your family, friends, and faith community.
- Take breaks. Pursue your hobbies. *Rest and rejuvenate*. To do this, you need to accept help when it is offered, and ask for help when it is not. These breaks are not selfish: if you don’t take them, the quality of your caregiving will suffer.
- Protect your mental and emotional health by joining a support group that is attended by other family caregivers. Look into getting individual counseling *before* you feel like you need it.