Development of The Family Care Inventory:
20 years of Nursing Research

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Drs. Minami, Takasaki & Sasaki, and esteemed nurse researchers. It is a great honor to be here in Tokyo again. I appreciate the opportunity to discuss with other scholars the complex issues in nursing and family care.

As the conference organizers recognized, family care, once one of the most personal and private matters in family life, is now an urgent, growing public health issue in the United States (US), Japan, and throughout the world. Family caregivers continue to be the most neglected group of providers in most health systems. In the US, families contribute $254 billion of unpaid services and support for ill or frail family members, more than double the annual spending on home health care and nursing home care.

The work I will discuss today is the product of many people and collaborations—first and foremost, Dr. Barbara Stewart, a psychologist and methodologist. Dr. Stewart's careful thinking and methodological expertise has been instrumental in crafting every study. I would also like to acknowledge Dr. Mark Hornbrook, the health care economist responsible for our cost analyses.

The context within which our work developed is similar to the context in Japan in some ways and very different in others. The demographic trends and relative percentage of elders are similar in both countries, but the relative percentage of elders is projected to grow more quickly in Japan. The health and social system in Japan is more highly developed in elder care than the systems in the US. The economies of both the US and Japan are challenged by the current and projected costs of care.

Family care presents complex issues for nursing and health policy. How can we balance family and societal responsibilities in care of frail and ill persons? From an ethical perspective, who should be responsible for the care of frail and ill members of the society? From a clinical practice perspective, how can the health system best support families in their role?

Our research has focused on understanding the family's perspective on family care, on developing measures of key concepts in family care, and on evaluating nursing interventions to strengthen family care. Today I will talk about the development of the Family Care Inventory (FCI) and its use in research and practice. Our goal was to develop measures that could be used in descriptive, correlational and longitudinal studies of family care as well as in intervention work. From the perspective of practice, we wanted the measures to have utility in identifying difficult family situations, identifying areas of family care that are going well, and tracking changes in family care over time. We also wanted the measures to have utility for population-based work with caregivers, for example, to assist providers in describing a population of families under their care and tracking the effects of changes in practice on families.

We have conducted ten studies of family care over the past two and a half decades. These studies focused on developing, evaluating or using the Family Care Inventory (FCI). The FCI has two components, one for the ill person and one for the family member most involved in providing care. The following scales are contained in the Caregiver Part of the FCI: Mutuality,
Preparedness for Family Care, Predictability in Family Care, Amount of Direct Care, Amount of Arranged Care, Amount of Help in Caregiving, Rewards of Caregiving, and Caregiver Role Strain.

In our first study we realized that family care was much more complex than had previously been reported (Archbold, 1982 a & b, 1983), some people did a great deal of direct care themselves, others arranged for care from others. Both approaches were difficult for some caregivers. In a subsequent qualitative study we identified other key variables important to understanding family care and how it is done, variables that had the potential to be altered by nursing.

We also realized the complexity of caregiver role strain, which we defined as felt difficulty in doing the family care role. We identified 11 discrete dimensions of strain including strain from, direct care, arranged care, communication problems, economic burden, feelings of being manipulated, increased tension, mismatched expectations, role conflict, worry, lack of resources, and global strain.

We used several strategies to enhance the content validity of the measure. First, we used the words of families in writing item stems and response options—items contained phrases that caregivers and elders used in Studies 1 and 2. As part of Study 2, twenty experts reviewed the draft items for content coverage and clarity. Below is a sample item from the strain from worry scale.

How much do you worry about who will take care of him or her if something happens to you?

0 Not at all
1 A little
2 Some
3 Quite a bit
4 A great deal

We obtained evidence for the reliability of the new scales. Most of the strain scales have high to adequate internal consistency. Because we wanted to use our measures with elders who had limited education, we made the readability level simple by limiting the number of words with three or more syllables. We have very little missing data across samples.

We obtained evidence for construct validity by testing hypothesized relationships among family care variables. Correlations supported the hypothesized relationships among concepts. For example, we hypothesized that preparedness for family care would be negatively associated with caregiver role strain from worry (r = -.45).

We also evaluated the measure's validity to capture change over time including change from intervention. In the Parkinson Spouses Study we used a known group approach to estimate the ability of the strain measures to detect change (Carter et al., 1998). We compared strain scores for caregivers caring for persons in different stages of Parkinson's disease by using the Hoehn and Yahr Staging scale, which categorizes disease stage according to mobility impairment:

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>Stage 1</td>
<td>Unilateral involvement.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Bilateral involvement without balance problems</td>
</tr>
<tr>
<td>Stage 2.5</td>
<td>Bilateral involvement with mild balance problems</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Mild to moderate bilateral involvement; some postural instability but physically independent.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Severe disability; still able to walk or stand unassisted.</td>
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<tr>
<td>Stage 5</td>
<td>Wheelchair bound unless aided.</td>
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</tbody>
</table>

Table 1. Internal consistency reliability of the caregiver role strain scales

<table>
<thead>
<tr>
<th>Scale Name</th>
<th># of Items</th>
<th>Cronbach’s ( \alpha )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strain from worry</td>
<td>11</td>
<td>.88</td>
</tr>
<tr>
<td>Strain from tension</td>
<td>4</td>
<td>.93</td>
</tr>
<tr>
<td>Strain from frustration due to communication problems</td>
<td>3</td>
<td>.93</td>
</tr>
<tr>
<td>Strain from direct care</td>
<td>51</td>
<td>.98</td>
</tr>
<tr>
<td>Strain from mismatched expectations</td>
<td>5</td>
<td>.57</td>
</tr>
<tr>
<td>Strain from economic burden</td>
<td>4</td>
<td>.75</td>
</tr>
<tr>
<td>Strain from lack of resources</td>
<td>5</td>
<td>.88</td>
</tr>
<tr>
<td>Global strain</td>
<td>4</td>
<td>.82</td>
</tr>
</tbody>
</table>
Persons in Stage 1 have very little functional impairment. Persons in Stages 4 and 5 are severely impaired in mobility.

We used a sample of 380 spouses of persons with PD. Stage 1: n=67, Stage 2: n=175, Stage 2.5: n=42, Stage 3: n=48, Stage 4/5: n=48.

Figure 1 depicts the mean level of caregiver role strain for spouses caring for persons in different stages of PD. Spouses caring for someone with greater disability from PD report higher strain than spouses caring for someone with less disability. These findings suggested that our measures would be sensitive to detect change, for example from an intervention.

We used the Family Care Inventory in correlational and predictive studies (Archbold et al., 1990). Figures 2 and 3 present predictors of strain at 6 weeks, and 9 months, after an elder was discharged from the hospital. Mutuality, or the positive quality of the relationship between the elder and the caregiver, declined from 6 weeks to 9 months. After controlling for 5 known predictors, gender, spouse vs. nonspouse, cognitive impairment, mobility and amount of direct care, mutuality explained 4 to 24% of the variance in CG role strain (median 12%). Mutuality explained variance in feelings of being manipulated, global strain, mismatched expectations about care, tension in the relationship, role conflict, and strain from direct care. It did not explain significant incremental variance in strain from lack of resources, economic burden from care, or worry.

After controlling for previous predictors and mutuality, preparedness explained 3 to 16% of the variance in caregiver role strain (median 6%). Preparedness explained significant increments in variance in seven aspects of role strain at 6 weeks.

Finally, after controlling for previous predictors and preparedness, predictability was associated (p<.05) with lower levels of CG role strain from lack of resources and worry at 6 weeks. Predictability explained increments in variance (5 to 15%; p<.05) in seven of the nine role strain measures at 9 months.

Interestingly, at 9 months, mutuality is still important in explaining strain, preparedness explains less variance than it did at 6 weeks, however, predictability explains significant increments in variance in seven aspects of strain. This suggests that families may expect the situation after hospital discharge to be unpredict-
Based on these findings, we wondered if we could improve the quality of family care for the elder and the caregiver with an intervention to design to increase skill & preparedness, increase enrichment (Cartwright et al., 1994) thereby increasing or preventing declines in mutuality, and increasing predictability in family care. We called the intervention PREP based on the three goals of increasing PReparedness, Enrichment and Predictability. We defined family as elder and whomever he or she identifies as family. PREP is designed to work with the family (all members who want to be involved, minimally the elder and one family member).

PREP was based on five principles: family focus, systematic assessment, multiple strategies tailored to the family, blending nurse and family knowledge, and transitions.

Two of the principles were facilitated with the Family Care Inventory: (1) family focus and (2) sys-
tematic assessment of family care. We administered the FCI within one week of the elder’s referral to home health care and used the FCI data to create family care profiles and summaries.

In figure 4 you can see the family’s score (the black Xs on measures of variables that help caregiving go well). The black dot indicates the score of the average caregiver—the gray bar indicated the middle 50% of caregivers in similar situations. You can see that this family caregiver has very high mutuality and rewards, but low preparedness and predictability.

The profile in figure 5 shows strain from caregiving activities; you can see that this caregiver has a lot of strain from arranging care and no strain from dementia related symptoms.

The next profile (Fig. 6) plots scores on difficulties in family care. This caregiver has very high strain from worry, somewhat high strain from lack of resources and increased tension, but average to low strain in other areas.

Finally, the family care summaries were designed to flag extreme scores at the item level, for example, worry
about leaving the care receiver alone when you have to go out.

The PREP nurse reviewed the profiles and summaries with the family and created a follow-up list of extreme scale or item scores (for example, low preparedness, and high worry). The family then reviewed the follow-up list and made any modifications they would like.

At that point, the nurse asked the family if there is anything on the list that they would like to work on with her. If the family chose an issue to work on, the nurse and family completed an in-depth assessment to get a comprehensive understanding of the issue. This process helped to build a partnership on which the PREP system of intervention is based (Harvath et al., 1994).

We developed an electronic charting system called the PREP e-chart that supported the intervention. Each screen was developed to support the intervention.

In figure 7 summarizes the issues selected by the family and nurse, and the strategies they tried to address them. As you can see, the issue being worked on was grief because of the sudden death of the caregiver’s mother and the caregiver’s fear and anxiety that were paralyzed to her. The strategies that the nurse and family implemented included: acupuncture therapy for anxiety, provision of information on phobias and panic disorders, and therapeutic massage.

In summary, the issues and concerns built on the results of the FCI assessment and were selected by families. This assessment was accomplished during the first two home visits, and then iteratively. Strategies were generated from an in-depth assessment and blending of caregiver and nurse knowledge.

We had extremely promising results from a pilot test of PREP. PREP families scored 1 SD higher on the Home Care Effectiveness Scale (Fig. 8), a measure asking them how much their home health care helped them in a variety of areas (Archbold et al., 1995). PREP families had average 3-month total health care costs that were $3,800 less than families in skilled home health, suggesting that PREP offset the use of more acute services (Miller et al., 1996).

We are in the now completing a randomized controlled trial of PREP compared to standard home health care in terms of elder and caregiver outcomes, including strain and rewards of family care, health, satisfaction with health services, utilization and costs of health and social services for the family, and costs for the health system.

We are assessing family care expenses for the family including costs of services, supplies, labor costs, expenses for environmental modifications, and lost opportunity costs. We are assessing health care costs including overall cost of care, efficiency of care, cost offsets from intervention, reduction of hospitalizations, reduction of emergency room visits, and induced demand.
for caregiver health services.

While we do not yet have outcome data from the trial, we have analyzed 5-month Home Care Effectiveness Scale data. The response options for the scale are: not at all, a little, some, quite a bit, and a great deal.

Using factor analysis to group items in subscales, we created 5 subscales using 36 of the 46 items. Their Cronbach’s alpha reliabilities were generally strong. The first subscale measures caregivers’ view that, because of working with their home health care provider, they are more prepared to give effective care. The second subscale, which contains only two items, measures the extent to which the caregiver has improved their ability to monitor their health problems and keep themselves healthy. The third subscale measures the extent to which caregivers feel more satisfied with and in control of their family care and health situation. The fourth subscale measures the extent to which caregivers think they are better prepared to work together with the health care system in providing care for their frail elderly family member. Finally, the last subscale measures the extent to which bereaved caregivers felt comforted by their work with home health care providers after their family member died. PREP continued to provide bereavement care and other desired assistance after the care receiver died.

We compared PREP and Standard Home Health (SHH) on the Home Care Effectiveness subscales at Month 5 after study entry (Fig. 9). PREP caregivers scored significantly higher than SHH caregivers on all five subscales, with a significance level of .01 for the first four subscales; and .03 for the 5th subscale, feeling comforted. Of particular note, when inspecting the absolute mean values, is that PREP appeared to be most effective in two areas, improving the caregiver’s ability to give effective care and helping bereaved caregivers feel comforted. On these two subscales, the average scores of the PREP group fell between a response of 2 and 3, or between a response of some and a response of quite a bit. Although PREP caregivers scored higher than SHH caregivers on the Own Health subscale, the mean values for both groups were relatively low.

Our next steps are to use the longitudinal FCI data to determine a brief risk screen for predicting increases in strain and declines in health, and to evaluate a self-administered web-based family assessment with feed-
Development of The Family Care Inventory

Conclusion

In conclusion, here are the things we would do again if we were starting over. We would embed our work in the experience of families, recognize that the context constantly changes and understand the economic costs of family care, for families, for the health system, and for society.

If we knew then what we know now—we might have accessed families earlier and not waited for a Home Health referral, which now indicates very severe and acute problems. We would also include biological measures to tease out the dynamics of health declines in caregivers.

References


