Preparedness for Care Giving Scale For Family Caregivers

Ms Chua Hui Chin Audrey, SSN
Authors

• SSN Chua Hui Chin Audrey
• SNC Sujata Rajaram
• NM Eileen Cheah
Family caregivers also referred to as informal caregivers, provide a level of care at home equivalent to that of professional burses.

They monitor patient’s acute or chronic condition, recognize impending problems such as side effects of medication, knowing how and when to respond and procedures such as dressing change.

Caregivers provide this high level of skill at home, however they often feel unprepared for care-giving and lack the knowledge and skills required to provide care.
Research has established that care giving is stressful and informal caregivers are at a high risk of adverse physical and psychological consequences of care giving.

Preparedness is care giving defined as perceived readiness for multiple domains of care giving role such as providing physical care, providing emotional support, setting up of in – home support services and dealing with the stress of care giving.

The aim is to evaluate care giver preparedness prior to patient’s transition from acute care settings to other health care settings.
Methodology

Preparedness for Care giving scale created by Archibald et.al in 1990 is a **caregiver self rated instrument** that consists of **8 items** that asks caregivers how well prepared they believe they are for multiple domains of.

Responses are rated on a 5 point scale:
- 0 to 4.0 = not at all prepared
- 4 = very well prepared

The higher the score, the more prepared the caregiver is, the lower the score the less prepared the caregiver is.
Results

 Preparedness for Caregiver Scale was used by the Geriatric trained nurses in two geriatric units.

 Total score achievable is 32. The scale was used on 18 caregivers:

 5 caregivers scored 30 to 32 meaning they were very well prepared for their care giving role.

 6 caregivers scored 20 to 23 meaning they were quite well prepared for their care giving role.

 4 caregivers scored 12 to 15, meaning they were not quite well prepared for their care giving role.

 3 caregivers scored 4 to 8 meaning they were not at all prepared for their care giving role.
Preparedness for Care giving scale is brief and easily self administered by the primary family caregiver.

In addition to the 8 item responses caregivers can specify in writing areas in which they feel unprepared to provide care.

The instrument however does not ask about specific knowledge or skill needs thus requires health care providers to specifically to ask.
## The Preparedness for Care Giving Scale

<table>
<thead>
<tr>
<th>YOUR PREPARATION FOR CAREGIVING</th>
<th>SCALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How well prepared do you think you are to take care of your family member’s physical needs?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>2. How well prepared do you think you are to take care of his or her emotional needs?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>3. How well prepared do you think you are to find out about and set up services for him or her?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>4. How well prepared do you think you are for the stress of care giving?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>5. How well prepared do you think you are to make care giving activities pleasant for both you and your family member?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>7. How well prepared do you think you are to get the help and information you need from the health care system?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>8. Overall, how well prepared do you think you are to care for your family member?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>9. Is there anything specific you would like to be better prepared for?</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>
The Preparedness for Care giving scale (PCGS) was administered to the wife and open ended questionnaire solicited the wife’s descriptions of how unprepared she felt.

Nursing services are needed after Mr. Tan’s hospital discharge to support patient’s and family caregivers to manage the physical and emotional effects related to cancer diagnosis and treatment.

The information gained can be used to refine home based nursing intervention to facilitate caregivers preparedness to enhance patient’s physical function and psychosocial adaptation, and ultimately the patient’s quality of life.
Geriatric Wards
Preparedness for care giving is operationally defined as how well prepared a caregiver believes he or she is for tasks and stress of care giving role (Archbald, Stewart, Greenlick & Harvath, 1992).

By providing accurate information at appropriate times, health care providers may relieve anxiety and help patients and spouses cope with cancer.

Research on informal caregivers addressed issues related to quality of life for family members who are frail.
Todd & Zarit (1996) stipulate that female caregivers are more burdened with the role of care giving than male caregivers. Female care givers may endure greater overall trauma and experience, fatigue, worry depression, anorexia and insomnia.

Stetz & Brown (1997) evolving grounded theory on care giving, the labor of care giving adds depth to the understanding of the centrality of family caregivers role and responsibilities.
During the second phase of the labor of care giving called taking care, the spouse manages the illness by providing physical care, comfort and support, and monitoring the loved one’s illness and responses.

The spouse manages the environment by seeking and obtaining information, organizational resources and interactions with health care providers.

During the phase of taking care, the spouse learns to live day by day, becomes an advocate, gains competency and constructs meaning about herself from the relationship with her spouse.
Mr. George Tan was a 68 year old retired teacher was diagnosed with stage 4 lung cancer.

Mr. Tan lived with his 64 year old wife in a 2 bed room apartment. He had two married children who had families of their own and lived away.

Doctors felt that there was nothing much they could do for Mr. Tan. Mr. Tan’s wife Mrs. Mary Tan was his main caregiver.
Case Study

1) How does a wife of a patient with lung cancer conceptualize her preparedness to care for the physical and emotional needs of the spouse?

2) In what way is a wife unprepared to care?
The wife’s belief about her unpreparedness to care was measured by the PCGS, by Archbald et.al (1990, 1992).

The original notion of preparedness, which was derived from role theory, in which socialization to a role is assumed to be important for role enactment and performance.

The PCGS is a self reported questionnaire that measures four perspectives of domain specific preparedness: physical needs, emotional needs, resources and stress.
The scale has 5 likert type items with possible responses:

- 1 = not at all prepared to 4 = very well prepared.
- Overall scores are computed by averaging the 5 items.
- Scores ranging from 1 to 4, the lowest score correlating with least preparedness.
- The range of scores for the sample was 2 to 4.

A sixth open-ended questions asking the wife to describe the ways she felt. The wife was asked to compare the PCGS and other forms being used to collect socio demographic and health information.
The nurses used the protocol and coordinated care with the patient, family, primary physician and community resources that consisted of 8 schedules.
Standard Nursing Protocol (SNIP)

- These protocols included:
  - Common myths and misconceptions
  - Caregiver and patient as partners in the recovery process
  - Caregiver management of patient’s care
  - Impact of illness and its management on caregiver’s health and well being.
  - Impact of care giving responsibilities on caregiver’s health and well being.
  - Strategies to promote closeness and bond with the caregiver.
  - Future concerns regarding disease process.
  - Limitation of resources for self care management.
DATA COLLECTION & RESULTS
Data Collection

- Data was collected from Mrs. Mary Tan.
- She was asked questions from the Preparedness for Caregiver Scale (PCGS).
- Mrs. Tan was a retired secretary, who has been a housewife for the past 10 years or so. Mrs. Tan was able to answer the questionnaire to the best of her ability.
Results

- PCGS-ITEM 1 to 5, Mrs. Tan reported greater improvement in preparedness in her role as a caregiver.
- She rated herself as pretty well and well prepared to take care of the physical and emotional needs of her husband.
- Mrs. Tan consistently rated her preparedness as high over time. She was well prepared to take care of her spouse.

<table>
<thead>
<tr>
<th>PREPARATION FOR CAREGIVING</th>
<th>SCALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  How well prepared do you think you are to take care of your family member's physical needs?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>2  How well prepared do you think you are to take care of his or her emotional needs?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>3  How well prepared do you think you are to find out about and set up services for him or her?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>4  How well prepared do you think you are for the stress of care giving?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>5  How well prepared do you think you are to make care giving activities pleasant for both you and your family member?</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>
Mrs Tan’s conceptualization of preparedness to care.

**Question 6** How do you feel prepared for care giving?

Mrs. Tan felt that her description of preparedness to care need to be grouped into:

a) prepared with practical information  
b) prepared for emotional responses  
c) prepared with resources for problem solving.

---

**PREPARATION FOR CAREGIVING**

<table>
<thead>
<tr>
<th></th>
<th>How well prepared do you think you are to respond to and handle emergencies that involve him or her?</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>
The wife believed that preparedness required having specific care for the husband, including managing symptoms such as pain, and managing complications.

Practical information was needed to meet emotional care of the husband, Mrs. Tan identified a need for practical information on dealing with the patient’s concern and meeting effective communication. Mrs. Tan’s emotional needs were noted as often as the patient’s emotional needs.
Mrs. Tan described the need for practical information on emotional self care, in particular fast and effective advice on how to manage personal feelings of frustration, uncertainty and ambivalence.
**Preparedness for Emotional Responses**

- Mrs. Tan felt that for her own and husband’s emotional consequences, she wanted to be forewarned of the likelihood of the specific feelings such as fear, apprehension, impatience, distress and unwillingness to care.

- She wanted to be told that she might feel distressed and sometimes feel too tired that she would be unwilling to care for her husband.
She wanted to be told that she might feel distressed in the event of metastasis, and prolonged role of a caregiver. Mrs. Tan wrote that preparedness to care meant being aware of likelihood of emotional reactions after specific events. For e.g. Mrs. Tan reported she wished to have known that distress may be caused by perceived loss of control.

Mrs. Tan also wanted to be prepared for the distress associated with resistance for the new role of family caregiver, loss of support from the spouse, conflicting obligations to home and family, and fear of the unknown. Preparedness for the likelihood of having these feelings may help the caregiver reduce the emotional impact and prevent it entirely.
Mrs. Tan identified several ways to be prepared with intrinsic and extrinsic resources including identification of social support, faith in spiritual power, (Mrs. Tan was a Christian) instruction on time management and awareness of personal strengths and weaknesses.

Social support was expected from medical social support, physician and nurses. Hope and prayer were relied on for spiritual strength. Mrs. Tan perceived self awareness as knowing one’s physical limitations, including self doubt and knowledge deficits.
Preparedness as a Process

- Preparedness for care giving as an ongoing process of skill attainment and refinement rather than an achieved state of readiness. The findings supported results from other studies.

- Sabo (1990) reported that spouses of patients with breast cancer perceived an inability to support and reassure their partners and were unprepared to deal with their partners’ anxiety and depression. Northhouse & Pter- Golden (1993) reported spouses as perceiving themselves as co-sufferers who responded and adjusted in tandem with the partner.
Literature Review

- Similar to other family caregivers the spouse of patient was not able to foresee the nature and intensity of the care giving work and had to learn to negotiate care giving responsibilities with professional caregivers and their spouses (Rutman, 1996).

- Preparedness to care is characterized by an ability to identify and adapt as needed. Northouse (1989) suggested that psychological support may not just be for the initial period but may persists over time for the patients and their spouses. They may need therapeutic support as they face challenges.
Burr, Leigh, Day & Constantine (1979) proposed that when people are prepared for or socialized to a new role, they are more likely to adequately prepare in the new role. Stetz & Brown (1997) identified learning to care for self as a consequence of managing the illness. Mrs. Tan considered self awareness as a resource.

Mrs. Tan felt consistently well prepared or very well prepared for most responsibilities. The results easily showed that Mrs. Tan was well prepared for the caregiver role.
Responsibilities associated with assuming a new caregiver role for Mrs. Tan has contributed initially to feeling of distress.

When patients and caregivers have positive expectations they are able to keep stress within manageable limits (Northhouse & Peter-Golden, 1993) and an optimistic attitude is relatively stable and resilient over time. (Scheirer & Carver, 1987).

Successful psychological adjustment of spouse of patient over the illness trajectory is characterized by the positive relationship between a sense of personal control and optimism (Morse & Fife, 1998).
Attention must be given to the positive and negative effects of the process of preparedness for care-giving on patients and caregivers relationship and identify points that correspond with the need for additional nursing intervention. Most caregivers could benefit from professional assistance and support to prepare for their role as caregivers particularly in the early part.

Targeting those with the greatest needs is a priority. A systematic and structured individualized intervention to assists Mrs. Tan to prepare for the role of the family caregiver may have a positive effect in the caregiver’s quality of life and the quality of life of the patient.
Implications for Practice

- The categories of preparedness can be used to assess specific learning needs of caregivers.

- The numerical scores of item 1-5 of the PCGS may be used to assess an individual’s estimation of preparedness along the illness. Caregivers can be encouraged to elaborate their preparedness in the open ended questions (which Mrs. Tan did).

<table>
<thead>
<tr>
<th>PREPARATION FOR CAREGIVING</th>
<th>SCALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well prepared do you think you are to take care of your family member’s physical needs?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>How well prepared do you think you are to take care of his or her emotional needs?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>How well prepared do you think you are to find out about and set up services for him or her?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>How well prepared do you think you are for the stress of care giving?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>How well prepared do you think you are to make care giving activities pleasant for both you and your family member?</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>
Strengths and Limitations

**Strengths**
- It is an easy to administer scale.
- The caregiver strain of Mrs. Tan and other caregivers was easily found.

**Limitations**
- It was done only on 18 caregivers which is not generalizable to a larger population.
Conclusion

- Nurses should assess the care situation and help family caregivers develop the skills they need. Caregivers who have these skills report lower levels of burden, stress, and distress, which may enable them to provide care that improves outcomes.

- Future research is needed on ways to enhance caregiver preparedness to care which is essential to preserve quality of life and facilitate patient recovery.
Caregiver Survival Tips

1. Plan ahead
2. Learn about available resources
3. Take one day at a time
4. Develop contingency plans
5. Accept help
6. Make your health a priority
7. Get enough rest and eat properly
8. Make time for leisure
9. Be good to yourself!
10. Share your feelings with others


...Thank
Aim of Study

- Research has established that care giving is stressful and informal caregivers are at a high risk of adverse physical and psychological consequences of care giving.

- However caregivers who report high level of preparedness for care giving, experience lower levels of caregiver strain after hospitalization of older adults.

- The aim is to evaluate care giver preparedness prior to patient’s transition from acute care settings to other health care settings.