Burnout In PD Patients And Family Caregivers

Dr. Paul Tam
Medical Director
The Scarborough Hospital
Toronto, Canada
Objectives

• To discuss how and why PD patients and the family caregivers experience burnout

• To discuss the strategies used in The Scarborough Hospital to prevent burnout
What is stress?

- Stress is a state produced by a change in the environment that is perceived as challenging, threatening, or damaging to the person’s dynamic balance or equilibrium.

- The stimulus that evokes this state is the stressor.

What is burnout?

- a “state of physical, emotional, and mental exhaustion caused by long-term involvement in an emotionally demanding situation”

Definitions of stress and burnout

**Stressors of PD patients**

Stressors of caregivers

Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

A PD patient …
Definitions of stress and burnout

**Stressors of PD patients**

Stressors of caregivers

Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

has to deal with many stressors
Psychosocial stressors

- Changes in social life
- Loss of independence
- Role reversal / changes – loss of income
- Fear of being alone
- Fear of dying

Physiological stressors

- Fatigue
- Sleep problems
- Restless legs, burning feet
- Shortness of breath
- Itching
- Side effects of medications

Logistical stressors

- Maintain a timetable for dialysis
- Keep track of clinic visits
- Accommodate delivery of dialysis supplies
- Maintain asepsis
- Listen to and comply with information

Definitions of stress and burnout

**Stressors of PD patients**

If any of the above stressors are not properly dealt with, burnout will occur.
Definitions of stress and burnout
Stressors of PD patients
Stressors of caregivers
Mechanism of burnout
Signs & Symptoms of burnout
Stress vs burnout
Consequence of burnout
Strategies to prevent burnout
Conclusion

Family member / caregiver ...
Who are they? …  

- Has personal ties to the care recipient
- Performs ‘caring’ activities that are directed to meet the physical, mental and emotional needs of the recipient
- Provides care without pay

Who are they? …

- Usually caring continuously without a break, i.e. “24/7” caregiver
- Have little or no preparation for the duties, but must acquire knowledge and skills in a hurry
- Don’t know who or where to call to get help

What do caregivers do?

- Meal preparation (76%)
- Transportation (54%)
- Coordinating appointments (30%)
- Managing supplies (27%)
- Comfort measures / symptoms management (19%)

Stressors of caregivers
Psychological stressors ...

- Produce feelings of frustration, embarrassment, guilt, anger, fear, love, and hate

- Complex feelings may lead to emotional exhaustion, helplessness, and depression
Psychological stressors …

- The caregiver and the dependant may be forced into unfamiliar roles or experience role reversal.
- Caregiver has to protect the client’s self-esteem.

Psychological stressors ...

- Client may become manipulative and aggressive, but give a different picture to outsiders

- Caregiver cannot obtain ‘job satisfaction’ because dependant becomes too demanding

Psychological stressors ...

- Caregiver may witness the growing debilitation of the patient, resulting in a feeling of guilt
- Unable to visualize positive changes for the future

Definitions of stress and burnout

Stressors of PD patients

Stressors of caregivers

Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

Physical stressors ...

• ↑ chance of physical illness

• ↑ level of physical activity - feeling tired and exhausted

• Physical fatigue
  Picot SJ. Nursing Research. 1995; 44:147-152.
Physical stressors ...

- Caregivers are often ‘old’ - greater potential for physical challenge
- May have medical issues themselves

Social stressors ...

- ↓ personal freedom
- ↓ quantity and quality of social contacts
- ↑ sense of isolation
Social stressors ...

- Neglected to attend own personal needs

- Feeling of being ‘trapped’

- Feeling that life opportunities have been lost
  Clifford D. *The social costs and rewards of caring*. Avebury, UK: Aldershot; 1990.
Financial stressors …

- Dealing with ‘normal’ medical treatment fees and costs of equipment
- Extra expenditure to cover laundry, special diet and transportation
- Forced to give up paid work to become full time caregiver

Financial stressors ...

- Older caregivers often live with a fixed income

- Unable to obtain paid employment due to responsibilities

- Lack of finances contributes to stress and burden of caring
Stressors to the family

- ↓ available resources to the rest of the family
- ↑ tension among family members
- Lack of privacy

Fink SV. *Nursing Research*. 1995; 44:139-146.
Definitions of stress and burnout
Stressors of PD patients
Stressors of caregivers
Mechanism of burnout
Signs & Symptoms of burnout
Stress vs burnout
Consequence of burnout
Strategies to prevent burnout
Conclusion

If any of the above stressors are not properly dealt with,
burnout will occur
Mechanism of burnout
(Figley’s Model)

Signs and symptoms of burnout
Physical S&S

• Feeling tired most of the time
• Feeling sick often
• Frequent headaches, back pain
• Change in appetite
• Change in sleep habits

Emotional S&S ...

- Sense of failure and self doubt
- Feeling helpless, trapped, and defeated
- Feeling alone in the world

Emotional S&S ...

- Loss of motivation
- Adopting a negative outlook
- ↓ sense of accomplishment
- ↓ sense of satisfaction

Behavioral S&S ...

- Sudden / gradual withdrawing from responsibility
- Becoming isolated from others
- Taking longer to get things done

Behavioral S&S ...

• Use food, drugs, or alcohol to cope

• Take frustrations out on others

What are the differences between Stress and Burnout?
<table>
<thead>
<tr>
<th>Stress vs Burnout</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stress</strong></td>
</tr>
<tr>
<td>Normal part of daily living</td>
</tr>
<tr>
<td>Eager to deal with situation</td>
</tr>
<tr>
<td>Feels situation is in control</td>
</tr>
<tr>
<td>Loss of energy</td>
</tr>
<tr>
<td>Leads to anxiety disorders</td>
</tr>
<tr>
<td>Primary damage is physical</td>
</tr>
<tr>
<td><strong>Burnout</strong></td>
</tr>
</tbody>
</table>

Definitions of stress and burnout
Stressors of PD patients
Stressors of caregivers
Mechanism of burnout
Signs & Symptoms of burnout
**Stress vs burnout**
Consequence of burnout
Strategies to prevent burnout
Conclusion
Consequences of burnout

- Placing patient in an institution
- Having another family member assume caregiver duties
- Patient neglect
- Patient abuse
- Patient exploitation, e.g., financial

Strategies used in The Scarborough Hospital to prevent burnout
Definitions of stress and burnout
Stressors of PD patients
Stressors of caregivers
Mechanism of burnout
Signs & Symptoms of burnout
Stress vs burnout
Consequence of burnout
Strategies to prevent burnout
Conclusion

The Scarborough Hospital, Toronto, Canada
Consider this …

- The needs of different caregiver are not the same
- Different types of support may be required at different stages of the caring process
- Interventions must be sensitive to the client’s culture
Information on supporting services …

- Purposes: to offer patient / caregiver
  - A degree of informed choice
  - A sense of control

Information on supporting services ...  

- Treatment regime
- Source of financial or legal aid
- Availability of community services
- Healthy coping and adjustment strategies
Adjusting dialysis Rx

• **Purpose**
  – To lessen the burden of performing exchanges

• **Adjust frequency of exchanges according to need** – 3x vs 4x / day

• **Use CCPD to decrease the frequency of manual exchanges**
Reinforce learning ...

• Purposes
  – To facilitate self management
  – To ↓ chance of complications
    • ↓ peritonitis, ↓ exit site infection
    • ↓ fluid retention
  – To ↑ knowledge for problem solving
Reinforce learning ...

- Clear instructions for PD procedures
- Clear instructions for using cyclers
- Know the side effects of medications
- Instructions for managing special diet
Emotional support ...

- Purposes
  - To provide patients / caregivers a chance to share their emotions
  - Emotional support is considered by caregivers as being the most important factor in home-caring

Emotional support ...

- Recognize and value the patients and caregivers’ work

- Patients who are peritonitis free for 2 years are acknowledged with a certificate and a voucher for shopping
Respite services ...

• Purposes
  – to relieve caregivers from day-to-day responsibilities
  – to allow opportunities for caregivers to attain ‘normality’ for themselves
  – to maintain a healthy relationship between the two parties

Respite services...

- Short stay in the hospital or nursing home for the dependant

Mon Sheong
Long Term Care Centre

Yee Hong
Long Term Care Centre
Respite services ...

- Skilled nursing services: community nurses perform exchanges as a form of home-based respite care.

Nurses from Community Care Access Centre do PD exchanges in patient’s home.
Respite services ...

- Home maker services: Government sponsored health care aides perform cooking and light household tasks

Personal Health Care Workers from Community Care Access Centre and Senior Community Agencies perform homemaking chores
Respite services ...

- Home delivered meals
Adult PD day care ... 1

- Purposes
  - To provide opportunities to break the monotony of dialysis at home
  - Allow patient to participate in organized activities
  - Allow caregivers to receive respite time

Definitions of stress and burnout
Stressors of PD patients
Stressors of caregivers
Mechanism of burnout
Signs & Symptoms of burnout
Stress vs burnout
Consequence of burnout
Strategies to prevent burnout
Conclusion

Adult PD day care ...
Psychotherapeutic: Family meetings

• Purposes
  – To address the entire family’s needs with family members meeting face to face
  – To assess dynamics of family members and plan strategies accordingly

Peer support ...

• Purposes
  – People helping people in dealing with similar stressors
  – Peer interaction is effective in steering a family caregiver toward a more positive attitude in his/her role

Peer support …

• Introduce new patients to patients who are experienced in dealing with dialysis issues

• Examples
  – Travelling aboard
  – General self care management
Benefits of preventing burnout
Benefits …

- Patients’ and caregivers’ quality of life is enhanced
- Patient and caregiver have more autonomy and control
- Family stresses are reduced

Benefits ... 2

- Episodes of institutional care are delayed
- Cost effective

Definitions of stress and burnout
Stressors of PD patients
Stressors of caregivers
Mechanism of burnout
Signs & Symptoms of burnout
Stress vs burnout
Consequence of burnout
Strategies to prevent burnout

If stressors are not properly dealt with,
burnout will occur
Even a devoted son cannot always be by the bedside of a parent with a chronic illness
Conclusion

• The medical team is uniquely qualify to help the CKD patients and their families to deal with various challenges

• The outcomes of these actions increase the family ability to cope and care for their loved one
Thank you for listening
Questions?