

Burnout In PD Patients And Family Caregivers

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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

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



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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

Brunner S, Bare B. *Textbook Of Medical-Surgical Nursing*. Philadelphia: Lippincott, 2000: 72.

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Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

What is burnout?

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

Nerenberg L. *Preventing elder abuse by family caregivers*. Washington, DC: National Centre of Elder Abuse; 2002.



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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

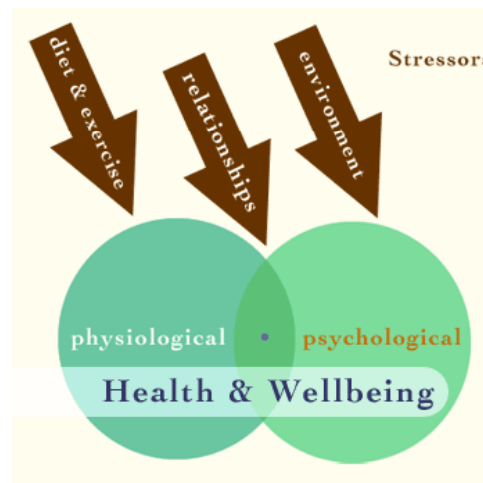
Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

has to deal with many stressors





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Stressors of caregivers

Mechanism of burnout

Signs & Symptoms of burnout

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Conclusion

Psychosocial stressors

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

Harwood L, et al. *Nephrology Nursing Journal*. 2009; 36(3):265-276.



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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

Physiological stressors

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

Harwood L, et al. *Nephrology Nursing Journal*. 2009; 36(3):265-276.



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

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

Harwood L, et al. *Nephrology Nursing Journal*. 2009; 36(3):265-276.

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,

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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 ...



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

Who are they? ... 1

- 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

Kitson AL. *International Journal Of Nursing Studies*. 1987; 24:155-165.

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

Who are they? ... 2

- 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

Kitson AL. *International Journal Of Nursing Studies*. 1987; 24:155-165.

Definitions of stress and burnout

Stressors of PD patients

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Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

What do caregivers do?

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

Beanlands H, et al. *Nephrology Nursing Journal*. 2005; 32(6):621-631.

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

Stressors of caregivers





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

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Conclusion

Psychological stressors ... 1

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

Sharp T. *Nursing Times*. 1992; 88:29-30.

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

Lea, A. *Nursing Standard*. 1994; 9:32-35.



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

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Psychological stressors ... 2

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



Sharp L. *Nursing Times*. 1992; 88:29-30.



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

Psychological stressors ... 3

- Client may become manipulative and aggressive, but give a different picture to outsiders
- Caregiver cannot obtain 'job satisfaction' because dependant becomes too demanding

Nolan MR, Grant G. *Journal of Advanced Nursing*. 1989; 14:950-961.



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

Psychological stressors ... 4

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



Nolan MR, Grant G. *Journal of Advanced Nursing*. 1989; 17:217-223.



Definitions of stress and burnout

Stressors of PD patients

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Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

Physical stressors ... 1

- ↑ chance of physical illness

Schultz R, et al. *Journal of Gerontology*. 1990; 45:181-191.

- ↑ level of physical activity - feeling tired and exhausted

Nolan MR, Grant G. *Journal of Advanced Nursing*. 1989; 15:544-555.

- **Physical fatigue**

Picot SJ. *Nursing Research*. 1995; 44:147-152.





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 ... 2

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



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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

Social stressors ... 1

- ↓ personal freedom
- ↓ quantity and quality of social contacts

Sharp T. *Nursing Times*. 1992; 88:29-30.

- ↑ sense of isolation

Boland DL, Sins SL. *Journal of Nursing Scholarship*. 1996; 28:55-58.





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

Social stressors ... 2

- Neglected to attend own personal needs
Boland DL, Sins SL. *Journal of Nursing Scholarship*. 1996; 28:55-58.
- Feeling of being 'trapped'
- Feeling that life opportunities have been lost

Clifford D. *The social costs and rewards of caring*. Avebury, UK: Aldershot; 1990.





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

Financial stressors ... 1

- 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

Sharp T. *Nursing Times*. 1992; 88:29-30.



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

Financial stressors ... 2

- 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

Sharp T. *Nursing Times*. 1992; 88:29-30.

Taking care of the carers, British Medical Association. BMA: London; 1995.



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Stressors of PD patients

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Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

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.

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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,

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Stressors of PD patients

Stressors of caregivers

Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

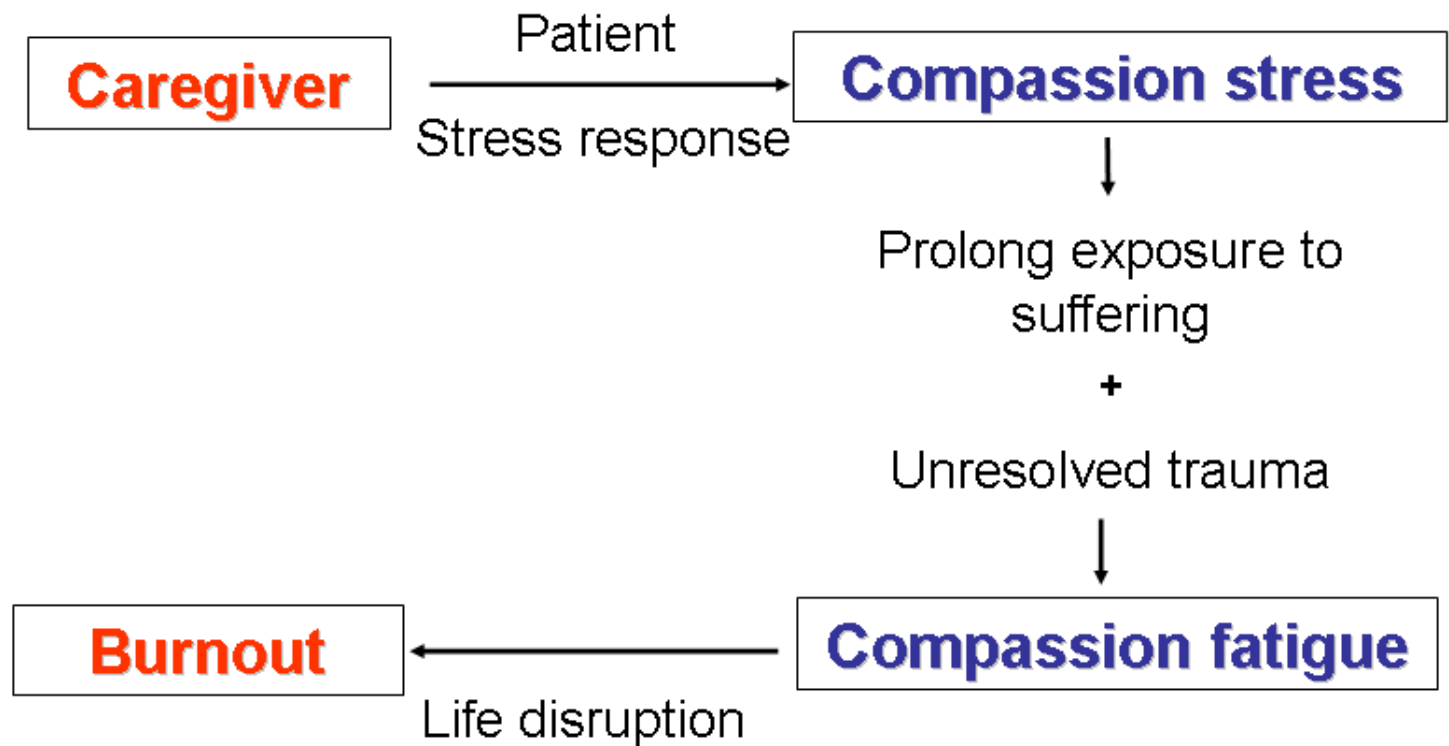
Consequence of burnout

Strategies to prevent burnout

Conclusion

Mechanism of burnout

(Figley's Model)



Figley CR. In: Figley CR, ed. *Burnout in families: The systemic costs of caring*. Boca Raton, FL: CRC Press; 1998:15-28.

Definitions of stress and burnout

Stressors of PD patients

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Mechanism of burnout

Signs & Symptoms of burnout

Stress vs burnout

Consequence of burnout

Strategies to prevent burnout

Conclusion

Signs and symptoms of burnout



**Signs 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

Caregiver burnout – Veterans Affairs Canada (1999). Retrieved September 29, 2009, from <http://www.vac-acc.gc.ca/clients/sub.cfm?source=health/caregiving/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

Emotional S&S ... 1

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

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

Guide to caregivers, 2009 – Saskatoon Informal Caregiver Centre. Retrieved September 29, 2009, from <http://www.caregive.sasktelwebsite.net/caregiverguide.html>

Emotional S&S ... 2

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



Guide to caregivers, 2009 – Saskatoon Informal Caregiver Centre. Retrieved September 29, 2009, from <http://www.caregive.sasktelwebsite.net/caregiverguide.html>

Definitions of
stress and
burnout

Stressors of
PD patients

Stressors of
caregivers

Mechanism of
burnout

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Symptoms of
burnout**

Stress vs
burnout

Consequence
of burnout

Strategies to
prevent
burnout

Conclusion

Behavioral S&S ... 1

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

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

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Behavioral S&S ... 2

- Use food, drugs, or alcohol to cope



- Take frustrations out on others



Guide to caregivers, 2009 – Saskatoon Informal Caregiver Centre. Retrieved September 29, 2009, from <http://www.caregive.sasktelwebsite.net/caregiverguide.html>

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

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

What are the differences between Stress and 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

Stress vs Burnout	
Normal part of daily living	Result from unrelenting stress
Eager to deal with situation	No desire to deal with situation
Feels situation is in control	Feels situation is hopeless
Loss of energy	Loss of motivation and hope
Leads to anxiety disorders	Leads to isolation and depression
Primary damage is physical	Primary damage is emotional



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Stressors of PD patients

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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



Pierce L, Lutc B. In Larsen P, Lubkin IM, eds. *Chronic illness: Impact and interventions*. 7th ed. Sudbury, MA: Jones and Bartlett Publishers; 2009:191-229.

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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

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

Definitions of stress and burnout

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Signs & Symptoms of burnout

Stress vs burnout

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Strategies to prevent burnout

Conclusion

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

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Stressors of PD patients

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Strategies to prevent burnout

Conclusion

Information on supporting services ... 1

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

Wolfe C, Rudd T, Beech R, eds. *Stroke services and research*. Stroke Association, London; 1996.



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

Information on supporting services ... 2

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

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

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

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

Reinforce learning ... 1

- Purposes
 - To facilitate self management
 - To ↓ chance of complications
 - ↓ peritonitis, ↓ exit site infection
 - ↓ fluid retention
 - To ↑ knowledge for problem solving



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

Reinforce learning ... 2

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



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

Emotional support ... 1

- 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

Pollock A. *Nursing times*. 1994; 90:31-33.

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

Emotional support ... 2

- Recognize and value the patients and caregivers' work

Mackenzie A, Lee D. In Redfern SJ, Ross FM, eds. *Nursing Older People*. 4th ed. Edinburgh, UK: Elsevier Churchill Livingstone; 2006: 713-727.

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



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

Respite services ... 1

- 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

Mackenzie A, Lee D. In Redfern SJ, Ross FM, eds. *Nursing Older People*. 4th ed. Edinburgh, UK: Elsevier Churchill Livingstone; 2006: 713-727.

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

Respite services ... 2

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



**Mon Sheong
Long Term Care Centre**



**Yee Hong
Long Term Care Centre**

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

Respite services ... 3

- 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.

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

Respite services ... 4

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



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

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

Respite services ... 5

- Home delivered meals



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 ... 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

Mackenzie A, Lee D. In Redfern SJ, Ross FM, eds. *Nursing Older People*. 4th ed. Edinburgh, UK: Elsevier Churchill Livingstone; 2006: 713-727.

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 ... 2



Peritoneal Dialysis Social Day Care
CareFirst Seniors' Centre



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

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

Mackenzie A, Lee D. In Redfern SJ, Ross FM, eds. *Nursing Older People*. 4th ed. Edinburgh, UK: Elsevier Churchill Livingstone; 2006:713-727.



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

Peer support ... 1

- 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

Pierce L, Lutc B. In Larsen P, Lubkin IM, eds. *Chronic illness: Impact and interventions*. 7th ed. Sudbury, MA: Jones and Bartlett Publishers; 2009:191-229.

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

Peer support ... 2

- Introduce new patients to patients who are experienced in dealing with dialysis issues
- Examples
 - Travelling aboard
 - General self care management



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

Benefits of preventing 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

Benefits ... 1

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

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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

Benefits ... 2

- Episodes of institutional care are delayed
- Cost effective



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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



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

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百孝經

但願繼吾志
何須求吾身

一 天地重孝孝道第一
 孝順能生孝順子
 孝是人道第一
 自古忠臣多孝子
 盡心竭力孝道貴
 孝道貴在心
 二 惜乎人間不
 諸事不順因
 孝道貴順無
 福祿皆由孝
 人人都可孝
 孝子口裡有
 三公婆上邊能
 女得淑名先
 孝在鄉黨人
 孝子達人就
 生前孝子聲價貴
 處世惟有孝力大
 一個孝字全家安
 孝順子弟必明賢
 孝子謝世即為仙
 君遠賢臣舉孝廉
 孝道不獨講吃穿
 孝親親責莫回言
 回心復孝天理還
 怎知孝能感動天
 孝順不分女共男
 天將孝子另眼觀
 孝敬父母如敬天
 孝婦面上帶孝顏
 又落孝來又落賢
 三 從四德孝在前
 孝在家中小歡
 孝化風俗人品端
 死後孝子萬古傳
 孝能感動地合天

久病牀前無孝子

Even a devoted son cannot always be by the bedside of a parent with a chronic illness

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

Conclusion

- The medical team is uniquely qualified 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?