



CARE FOR CAREGIVERS



OBJECTIVES



- Discuss the overview of HIV/AIDS caregiving
- Identify causes of caregiver burnout/burden
- Identify factors contributing to caregiver burnout
- Explore ways to manage and prevent caregiver burnout



OVERVIEW OF HIV/AIDS CAREGIVING



- Two types of caregivers provide clinical and supportive services to people with HIV/AIDS.
- Formal caregivers include health professionals, behavioral health specialists, and social workers who are trained and compensated for their care giving activities.
- The trained volunteers and spiritual counselors associated with AIDS service organizations and AIDS care team also fall in this definition category.



OVERVIEW OF CAREGIVERS



- Informal caregivers include relatives, spouse/partners, and friends who provide in-home care.
- These caregivers vary in the types of tasks performed, the amount of time devoted to care giving, and living arrangements (i.e. same or different household)



ROLES OF INFORMAL CAREGIVERS



Informal caregivers perform a variety of roles that help PLWHAs adhere to treatment regimens, reduce reliance on formal caregivers, remain at home longer and maintain quality of life. Traditionally, family members have served as primary caregivers for seriously ill individuals. HIV care involves more diverse social networks; as such lovers, friends and other chosen kin are carers.



ROLES OF INFORMAL CAREGIVERS



Some of their tasks include:

- Emotional support (e.g. comforting, empathizing, and providing encouragement)
- Helping with activities of daily living (e.g. feeding, toileting, bathing, washing, etc.)
- Helping with errands, cleaning the house, arranging or providing transportation
- Management of financial and legal management
- Nursing care
- Health care advocacy



REWARDS OF CARE GIVING



Rewards of caregiving:

- Brings mission and purpose to caregiver's life
- Helps caregiver develop empathy and self-knowledge
- Helps caregiver gain a sense of personal effectiveness by demonstrating competence under very difficult circumstances
- Helps caregiver experience the positive feelings associated with loving, caring, and feeling needed.



BURDEN AND REWARDS OF CAREGIVING



- “Burden” describes the physical, emotional, financial, and social problems associated with care giving.
- Burden assesses the extent to which care giving disrupts daily routine and social relationships and negatively affects resources, e.g change in household routines, missed days of work, family frictions, reduced social contacts, loss of income, etc. Some may report feeling of nervousness or depression about their relationship with the patient.



CAUSES OF BURDEN INFORMAL CAREGIVER



- Caregiving usually comes as an unexpected role; to assume this role, one must restructure pre-existing roles, obligations, and social activities.
- The physical demand contributes to a burden unlike those of formal caregivers because informal caregivers are required to perform multiple and sometimes conflicting roles.
- The non-normative experience of caring for someone with a terminal illness can be a major source of emotional stress, especially for younger caregivers.



CAUSES OF BURDEN FOR FORMAL CAREGIVERS



- Many burdens experienced by both formal and informal caregivers are the same.
- Other burdens are unpredictable due to the course of HIV disease and the range of potential complications.
- Workplace-related stressors, such as work overload, unrealistic expectations of what can be accomplished, lack of decision making autonomy, communication problems, and role conflict also exist for formal caregivers.



FACTORS CONTRIBUTING TO CARE GIVER BURNOUT



INDIVIDUAL

- Age—younger caregivers more subject to burnout
- High expectations of oneself & others
- High levels of commitment, dedication, and idealism
- Difficulty saying no
- Difficulty delegating responsibility to others
- Propensity toward self-sacrifice
- The need to work hard



FACTORS CONTRIBUTING TO CAREGIVER BURNOUT



SITUATIONAL

- Role ambiguity
- Conflict between role demands
- Work overload
- Job tension
- Interpersonal conflict (with recipient, family members, colleagues, etc)
- Insufficient resources to meet needs
- Inadequate social support



ASSESSING CAREGIVER BURDEN



The early detection of caregiver burden conserves resources by preventing or reducing medical visits for psychosomatic complaints

These can be assessed by health professionals by asking a few questions:

- Do you feel under a lot of stress currently
- What aspects of the day are most stressful
- Have you been feeling down, anxious, or irritable lately
- Do you have any outside help
- Do your friends and family watch care recipient for you so that you have time for yourself
- What do you do to relieve your stress and tension



COUNSELING CAREGIVERS



- Need to maintain integrity (desire to be knowledgeable about the disease and preventing OIs)
- Need to feel worthwhile and useful
- Need to learn and communicate
- Need to act according to a set of beliefs and values
- Need for continuity of care



COUNTERACTING BURNOUT & PROMOTING SELF-CARE



- Help caregiver educate him/herself about the care recipient's condition
- Encourage caregiver to ask questions when accompanying the recipient to medical appointments
- Encourage caregiver to keep a journal to record events that cause stress in their life
- Encourage caregiver to seek professional help if efforts are not working



COUNTERACTING BURNOUT AND SELF-CARE



- Encourage caregiver to break down tasks. (Let go. No one person can do it all. Acknowledge that as human, you have limitations just like everyone else.)
- Help caregiver adopt relaxation techniques that fit in with his/her interests, time, and resources.
- Encourage caregiver to strive for good health—healthful lifestyles play an important role in burnout prevention.



COUNTERACTING BURDEN & PROMOTING SELF-CARE



- Encourage caregiver to maintain a life outside the care giving role. It's encouraging to take regular breaks and to keep up with interests and hobbies as best as he or she can.
- Help caregiver “jump-start” the self-renewal process by linking him/her with social support resources
- Encourage caregiver to build a support network to provide emotional comfort, practical support, reduce social isolation, and offer humor, recognition, and encouragement.



CONCLUSION



- Over the past decade, improved antiretroviral regimens, concerns about the costs of inpatient care, and consumer preferences have shifted HIV care from hospitals to home and community-based settings.
- This shift has placed heavy demands on the family and friends of HIV-positive individuals, many of whom have very little knowledge of HIV management or available resources. Although HIV+ individuals are living longer, many are developing therapy-related side effects that require monitoring and management in the home.
- By systematically assessing the causes and levels of stress in informal caregivers, health professionals can offer education and counseling that is more responsive to individual needs.



THANK YOU

