resources from the implementation team, the virtual learning collaborative model appears to be the more effective means of providing implementation support to rural primary care practices.

IMPROVING HEART FAILURE MANAGEMENT THROUGH THE UTILIZATION OF CAREMAPS


Heart failure (HF) affects nearly 6 million people Americans. Health outcomes of HF patients are optimized when there is social support. However, there is a limited understanding of the extent to which formal and informal caregiving is available to HF patients. The aim was to characterize the depth and breadth of patient’s social networks and formal support in HF and to ascertain its impact on HF self-management. HF patients and one informal caregiver were recruited through Stanford HF Clinics and completed 45 min in-person, semi-structured interviews aimed at understanding patients’ social networks, including the closeness of relationship, roles, frequency of contact, and mode of communication. A diagram, called CareMaps, was developed based on these interviews and shared with dyads. A total of 17 dyads (n=34) participated in the study. The mean age of patients and caregivers was 66 ± 14 years and 58 ± 12.2 years, respectively. Nine of the caregivers were either spouses or significant others. The mean number of caregiving relationships were 4.47. While some patients had a rich network of geographically proximal and distal informal caregivers, others relied primarily on their informal caregiver who was interviewed. Dyads with greater connectivity perceived more ease in HF self-management and greater empowerment. CareMaps often revealed duplication or gaps in care and resources. Visualizing social networks show variability and can highlight gaps in care. HF patients, informal caregivers and providers may use CareMaps to determine the availability of support as well as gaps. This may optimize patient self-management while distributing caregiving responsibilities across multiple people.

INFORMAL NETWORK SUPPORTERS MAKE A DIFFERENCE IN FACILITATING USE OF FORMAL SUPPORT SERVICES FOR ELDER ABUSE VICTIMS


The hidden nature of elder abuse remains a major challenge in the field. Few elder abuse victims ever seek or receive assistance from formal support services (e.g., adult protective services, law enforcement) designed to ameliorate the effects of abuse and prevent re-victimization. This study examined whether the presence of a third-party “concerned person” in a victim’s social support network plays a role in enabling formal support service utilization. A representative population-based survey administered to a random sample of adults (n = 800) in New York State identified 83 cases of elder abuse from the past year. Penalized likelihood logistic regression was used to examine the relationship between availability of a concerned person and victim use of formal support services. Elder abuse victims who had a concerned person in their personal network were significantly more likely to use formal elder abuse support services than victims without a concerned person. Additionally, elder abuse victims who lived with their perpetrator were significantly less likely to use formal support services. Third-party concerned persons in a victim’s social support network represent a critical population to target in prevention efforts designed to promote elder abuse victim help-seeking and participation in the formal support system.

MANAGEMENT OF DISEASE IMPACTS AND GOAL SETTING IN RARE, SEVERE, PEDIATRIC HEALTH CONDITIONS

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Socioemotional selectivity theory describes how individuals with limited life expectancies and poor functional health (e.g., older adults) often prioritize short-term, emotion-based goals above the longer-term goals that younger, healthy individuals may target, such as knowledge acquisition. Children born with severe, degenerative, incurable chronic illnesses experience a discrepancy between the “on-time” expectation that adolescents and young adults prioritize future-oriented goals and the “off-time” emotion-based goal-setting that is most relevant in the context of their physical limitations and shortened life expectancies. This research evaluates goal-setting in Barth Syndrome (BTHS), a rare genetic condition among males characterized by cardiac complications, fatigue, weakness, infection, and growth delay experienced from birth. Few men with BTHS survive to midlife. Hourlong face-to-face interviews were conducted with 33 individuals with BTHS (ages 2 to 34) and/or their caregivers. Participants reported prioritizing short-term, emotion-based goals focused on symptom control and personal relationships, as opposed to longer-term goals such as pursuit of higher education or professional careers. Individuals with BTHS selected limited goals (e.g., modified participation in activities) and compensated for their lack of abilities (e.g., by using assistive devices). Participants primarily reported using secondary coping mechanisms (emotion management and downward comparisons) to manage the impacts to physical functioning and risk of early mortality. Boys learned how to practice goal selection from their caregivers who helped to manage their participation in activities. Individuals with BTHS reckon with the limited feasibility and value associated with investing in longer-term activities focused on knowledge acquisition, more closely resembling older adults than their age-peers.

NATIONAL SURVEILLANCE TO CLOSE THE GAP: UNDERSTANDING HEALTHCARE ACCESS BY AGE IN THE DEAF COMMUNITY

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Access to healthcare depends on cost, physical accessibility, social barriers, and patient satisfaction, as well as availability of care. Available evidence suggests that lower rates of healthcare access and higher rates of delay and