

The emerging and empowering roles of online mutual help groups in patient care. E.J. Madara. American Self-Help Group Clearinghouse, Saint Clare's Hospital, Denville, NJ.

Similar to their community face-to-face counterparts, online self-help support groups for genetic illnesses are providing more and more patients and families with comparable social support, education, and opportunities for needed advocacy. Unlike traditional support groups, online networks are overcoming many longstanding barriers to group participation, to include: rarity of the disorder, lack of transportation, 24-hour-a-day caregiver responsibilities, and limitations of most severe disabilities and illnesses. Through well-trafficked web site message boards, mailing lists, real-time chat rooms, and newsgroups, members are meeting their needs for understanding, normalization, practical information, coping skills, positive role models, "helper therapy," and "learning within community," while pooling and creating new "experiential knowledge" databases of their own. The Internet also empowers these "prosumers" with comparable access to medical knowledge databases. An increasing number of medical professionals and researchers are developing partnerships with these online groups, helping to interpret medical research and literature, sharing expertise, providing health information, and learning more about patient experiences and needs. The Internet is therefore breaking down the rigid social boundaries between doctors, patients, and researchers - and helping all to better understand the common role they play as colleagues and partners in online health learning.

Implementing Telemedicine & Principles, Practices, and Issues –  
A Perspective from Georgia

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Telemedicine/Telehealth/eHealth: Health care, health management, and health education related activities carried out by health care and health services professionals and/or consumers, that are delivered and/or facilitated using appropriate telecommunication and information management technologies. The goal is to make cost-effective health care more readily available to those in need at both the place and time of need. Example operational models include (a) Acute and consultative care wherein specialty resources are projected from centers to individuals and localities in need thereby empowering local providers and enhancing local services, (b) Chronic/managerial care wherein individuals coping with chronic disease and age related problems during their daily lives have improved access to appropriate monitoring capabilities and management support services, and (c) Store and forward systems that allow information and/or services to be requested and provided at the convenience of both the consumer and the provider. In each model, a clinical services orientation clearly defines technical requirements, and as a result brings into focus for resolution the issues of technical adequacy and reliability.

The appropriate telemedical technology is the least sophisticated, least expensive, and most readily available technology capable of delivering the required service. Issues of reimbursement and professional licensing are current and real. However, they will gradually and inevitably succumb to the demand created by successful, value-added solutions to individual and community needs for acute and chronic health care services that cannot be locally supported.

It is inevitable that increasing familiarity with telecommunications and information management technologies will expand their roles in the industry of health care. The diversity and effectiveness of these tools in the successful fulfillment of those roles will depend upon satisfied consumers, providers, and payors who will forge new partnerships in health care. Examples provided will illustrate models to consider, but applicability depends upon local analysis.