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Patient Support Groups are an Important Component of Your Toolbox for Patient Education[☆,☆☆]

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Nurses' role as patient advocate includes identification of resources for children affected with chronic medical conditions and their caregivers, including accessing peer-based support (i.e. patient support groups). To be effective advocates for patients, it is important for nurses to be knowledgeable about patient support groups (PSG) in order to direct patients to a PSG that matches their needs provides additional means of support related to living with their chronic health condition. Patients and families rely on nurses for recommendations to find the types of support that will help them to best manage their health condition. As part of the nurse's assessment of the patient's educational needs and their support system, it is important to include questions about whether the patient has experience with a PSG or is interested learning about what PSGs offer.

The history of patient support (PSG) or self-help groups dates to the 1930's, with the formation of Alcoholics Anonymous and progressed to include self-help support systems that provided assistance for groups to develop (i.e. self-help clearinghouses). Later, international networks were developed (International Network of Mutual Help Centers) in synch with a movement to create social change to improve relationships among people and healthcare providers/systems. Advances in technology, such as the Internet and social media, expanded access to information about PSG and allowed the development of PSG to flourish. This has been particularly important for patients with rare diseases and especially for those who live in remote areas to connect and communicate (Hu, 2017).

Three decades ago, Dr. C. Everett Koop, Surgeon General, and Dr. Faye Abdellah, Deputy Surgeon General, of the United States Public Health Service, sponsored a Workshop on Self-Help and Public Health to bring together representatives from self-help groups, healthcare professionals, academicians, and public policymakers to discuss ways to work together for the benefit of public health. In his address to the workshop, Dr. Koop stated, “I believe in self-help as an effective way of dealing with problems, stress, hardship, and pain…Mending people, curing them, is no longer enough; it is only part of the total health care that most people require. (Services UDoHaH, editor The Reports of the Surgeon General. The Surgeon General's Workshop on Self-Help and Public Health, 1987)”. The recommendations from this workshop helped shape public health policy to promote and enhance the development self-help groups.

Patient support groups are defined as a group of people with similar experiences and concerns who provide emotional support, coping strategies, and firsthand information about a medical or mental health condition or treatments (Hu, 2017). The roles and functions of patient or peer-based support groups may include: shared learning about health condition, emotional and moral support, identity support based on shared condition/experience, reduce feelings of isolation, empower for self-advocacy, advocacy for chronic illness, advice on lifestyle and coping mechanisms, guides/advice for school and travel, and increase public awareness about medical or mental health condition. Participants in PSG can benefit by gaining perspective through learning about what can be expected emotionally, physically, financially, and socially related to the diagnosis and treatment of a chronic medical/health condition. Also, PSG assist members to feel empowered in a situation that may induce feelings of helplessness by seeing how others in similar situation coped and by helping others. A recent study identified cultural differences in support needs of patients, so it is important to assess cultural preferences of the patient when evaluating the best fit with a PSG (Kreitschmann-Andermahr et al., 2018). In addition, some PSG are focused on providing support and education for family members, caregivers, friends, of someone with a chronic medical condition.

The National Institute of Mental Health classified three types of PSG: groups for people with mental or physical illness, recovery groups for people with addictions or compulsions, and groups for specific minorities such as the handicapped. There are various models used by PSG, including professional expert led, peer participatory, or peer participatory with professional expert as consultant. Support groups may be sponsored by a nonprofit agency, healthcare or community organization, or may be independent. PSG value autonomy and ownership of the group with recognition, support, and cooperation from healthcare professionals.

Activities of PSG may include: newsletters, web sites, conferences, social media, online chat groups, educational materials, referrals to health care providers, advocacy for changes in policies, laws, or practices, and information on clinical trials. The impact of PSG extends beyond the personal benefit to members to influencing changes in professional heath care practices by identifying shortcomings or

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[☆] The Pediatric Endocrinology Nursing Society (PENS) is committed to the development and advancement of nurses in the art and science of pediatric endocrinology nursing and to improve the care of all children with endocrine disorders through the education of the pediatric healthcare community. To aid in achieving that goal, the purpose of the PENS department is to provide up-to-date reviews of topics relevant to the PENS membership and to the general readership of the Journal of Pediatric Nursing.

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deficiencies in the approach to care of patients, involving patients in healthcare decisions, and advocating for research.

There is a growing body of research to support the effectiveness of PSG to promote health, improve health outcomes, and improve the quality of life for persons affected with chronic health conditions and their caregivers (Services UDoHaH, editor The Reports of the Surgeon General. The Surgeon General's Workshop on Self-Help and Public Health, 1987). Studies report that participation in PSG may reduce hospitalizations, reduce mood disturbances (Jensen, 1983; Spiegel, Bloom, & Yalom, 1981) and improve self-management of the participant's medical condition (Schottenfeld et al., 2016). PSG are an important avenue for research to identify interventions to improve health outcomes. Recently, crowdsourcing has emerged as a healthcare platform based on input from healthcare users; it is used by clinicians for diagnosis and treatment, for collaboration in large-scale health projects, and for research studies (e.g. PregSource®), as well as websites such as PatientsLikeMe, for patients to share experiences.

Barriers to engagement in PSG may include lack of awareness, time constraints, and confrontation of negative aspects of the chronic illness (Hu, 2017; Waite-Jones & Sweallow, 2018). In addition, location may be an issue for in-person groups, while access to the Internet may be a problem for on-line forums. Privacy concerns are an important consideration, particularly for online/social media-based groups. Recent news, such as Facebook's privacy violations, raise concerns for individuals and online health groups (Fung, 2018; Richards, 2018). Issues such as whether posts could be reposted (even in closed groups) or whether health information data could be shared (or sold) with advertisers remains a valid concern particularly in light of recent news that Facebook had approached several health organizations about sharing anonymized user data related to medical diagnosis and prescription information. Some countries, such as the United Kingdom have laws that require companies to request permission to collect data and report any data breaches (Matloff, 2018). Also, there are privacy concerns related to parents who post on social media with medical information about their child; even without using the child's name their child's privacy may be compromised. Some parent-focused PSG require the use of an avatar to protect both the parent and child's privacy.

What elements should the nurse evaluate in order to provide guidance to their patient about PSG? Listed below are important factors to consider to determine if a PSG is reputable and a good match for your patient.

1. Identify the goal(s) of the patient interested in joining a PSG.
2. Consider the size of the group; does patient prefer small or large groups?
3. Membership categories (patients, family members, friends, etc.)
4. Format of PSG (in person meeting, online chat group, etc.). Does the PSG screen members; is the chat room or social media site moderated?
5. Purpose of group (education, support, advocacy, etc.). Are the objectives or mission statement of the PSG in line with the patient's interests and goals?
6. Group model (professional led, peer participatory, other).
7. Quality of educational material provided. Does the PSG collaborate with a healthcare professional advisor(s) to review medical information? Are non-healthcare persons giving medical advice?
8. Cultural preferences should be addressed including values, perceptions of health condition, and comfort with various types of support. For example, in some cultures there may be a preference for self-sufficiency and independence, while other cultures the extended family may be involved in providing ongoing care.

The Healthfinder.gov web site of the Office of Disease Prevention and Health Promotion (US Department of Health and Human Services) is an excellent resource for locating support groups:

https://healthfinder.gov/FindServices/SearchContext.aspx?topic=833

In general, non-profit PSG that collaborate with healthcare professionals, are a good choice for patients seeking both education and support. The nurse should elicit feedback from patients about their experiences with PSG, including what they found helpful, and any negative aspects.

Nursing Implications

As advocates, nurses have the responsibility to educate patients with about the resources and tools available to improve health outcomes. By enhancing their knowledge about PSG and other community resources, nurses can empower patients to improve self-management of their health. The nurse should counsel patients that their experience may not be like someone else's story and to address any of their concerns with the healthcare team. Also, a word of caution is warranted about the potential for finding incorrect information on the Internet or from other patients, and the importance of checking with their healthcare team regarding any discrepancies or concerns. In addition, there are numerous opportunities for nurses and PSG to collaborate, including sharing their expertise at a PSG meeting, serving on the board of PSG, serving as a consultant to review educational materials with the PSG, and inviting PSGs to participate in a nursing conference.

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