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HCV Empowerment Groups: Support, Education, and Advocacy

In a collaborative effort between methadone maintenance treatment program clients and staff, we have developed a multifunctional group of support, education, and advocacy. This group had a natural evolution which began with supportive and educational activities, and ultimately led to group advocacy efforts.

Initial educational sessions focused on the steps involved in pre-treatment evaluation of HCV including interpretation of hepatitis C viral load and genotype tests, and the importance of the liver biopsy. The group helped to destigmatize the liver biopsy and interferon-based therapy. The support component evolved through group discussion of individual experiences with the evaluation and treatment process. These verbalized experiences allowed the group to identify barriers in HCV evaluation. Consequently, the group became motivated to address these barriers through advocacy activities. The group also engaged in efforts to raise community awareness about HCV.

These support, education and advocacy groups empower clients have a voice within their own treatment programs and in the community. Furthermore, these groups have the potential to influence adherence to treatment as participants share their individual successes in the HCV evaluation and treatment process with the group and these verbalized experiences become powerful motivators for others to engage more actively in their own treatment

Components and Development of HCV Empowerment Groups:

Group facilitators: Our group was originally facilitated by two clinic staff members who had a clinical relationship with most of the group members. While this need not be an essential aspect of the relationship between the group facilitator(s) and the group participants, the clinical relationship can be a powerful component in these groups. Positive feelings (e.g., of support, healing and safety) in the clinical relationship may promote the transfer of similar expectations to the group setting. These positive feelings encourage clients not only to consider a first meeting but also to remain actively involved in these groups.

Facilitators serve different roles in the group: They clarify misconceptions about the disease and treatment; promote a sense of safety; reinforce educational messages and supportive behaviors among members; and help identify supportive partnerships. The facilitator serves as a role model for members as they emerge as co-leaders. Over time, clients will emerge as co-facilitators.

Raise awareness of HCV in the clinic or program setting: HCV is the leading cause of death in our clients, and is a potentially reversible disease. Beat the HCV drum! Discuss HCV at staff meetings. Post news articles, flyers, and informational materials in a dedicated area in your clinic and start a HCV bulletin board and literature rack. Create a formal or informal portfolio of interesting materials gathered by group members.

Become an expert on HCV, even if you aren't one now: A group leader must develop expertise on the subject: This means knowing enough about HCV to teach the basics and to help dispel myths about the disease.

Identify leaders: Every clinic has clients who have leadership abilities and experiences. Some are already recognized as leaders (e.g. Patient Advocacy Committee leaders); others will emerge in the course of meetings and projects. Opportunities to identify leaders include asking members to volunteer with the recruitment and orientation of new members, setting up and cleaning up the meeting space, speaking at and facilitating meetings. Encourage leaders to accompany patients who have less social support to

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medical procedures and make hospital visits. By acknowledging leaders for their work, others are motivated to step forward in leadership roles. A culture of self help and education is developed.

Link individual recovery and treatment to group goals: Fighting back against the HCV epidemic is achieved when individuals make steps towards their own work-up and treatment: Acknowledge these accomplishments in the context of the group's evolution. The group progresses when an individual within the group progresses.

Promote Group identity: Coming up with a name and mission statement as a group process will enable group members and clinic staff to take ownership of the group. Encourage members to design logo, flyers and slogans. Take a meeting to post a large sheet of paper on the wall, and write down mission statement ideas as they are expressed.

Look for opportunities for advocacy: Engaging in individual and group hepatitis c advocacy efforts can be a motivating force in itself, resulting in patients addressing longstanding health and addiction issues with a new focus. Advocacy work can include local petition campaigns, staffing hot lines, information tabling. Simple advocacy projects can become pivotal movements within the community.

Create a galvanizing event: Find or create an event in your community that will focus the group's creativity, talent, and energy. Consider a local liver walk, fundraiser, street fair, petition campaign, picnic or conference: Creating a splash early on will heighten the groups profile, attract members and supporters, raise awareness of the issue, and create leadership opportunities. Group members will begin to think "out of the box" and interact in new ways. Patients who are not ready to confront their individual issues may be more likely to participate in a group event. It is also an opportunity to interact with like-minded groups, form alliances, and receive recognition and publicity.

Advertise for your support group through multiple venues: Create or recruit others to create attractive, informative and attention getting flyers. Flyers are necessary props; however personal recruitment is essential to bring in members. Enlist your core leaders in this task. Make sure announcements for HCV support groups are made at other clinic groups and activities. Interoffice email to staff announcing upcoming groups and ask for assistance in group recruitment

Every group is an event: Attendance at meetings may vary, and if attendance dwindles it can affect group morale. Emphasize that every meeting is an event (even if two people attend, that meeting can precipitate life changing action steps) Emphasize positive aspects of all meetings, and share outcomes of previous meetings in future groups.

Consider all administrative issues: Work with clinic administrator, interceptors, and nurses to avoid disruption of clinic services. This is especially important when large groups meet and adjourn: Make sure staff time is protected so patient care does not suffer and solicit the support of fellow staff members for coverage.

Document everything: keep flyers, attendance lists, newsletter articles, etc. documenting what you are doing: This is your group's history, and could be the basis of soliciting donations or grants.

Create a HCV Peer Education Program: Peer education naturally evolves out of the empowerment group. As group members become knowledgeable about key HCV issues and develop ways to communicate about these issues, develop a simple, but formal program to train peer educators. You can ally with other HCV organizations to deliver a curriculum leading to peer education certificates.