

Newfound Friends: A support group for adolescents with cancer

Kathryn Hustins

Abstract

Adolescence is a developmental period greatly characterized by change. The experience of cancer at this life stage often impacts on normal development of body image and self-concept, relationships with others, autonomy and sense of identity and life direction. Newfound Friends is a support group for adolescents with cancer and/or those who have survived cancer. The purpose of the group is to promote positive psychological and social health. The article describes the goals, membership and format, as well as the activities of Newfound Friends. This group could be easily organized in other provinces by nurses who work with adolescents or young adults coping with cancer.

Developing cancer in adolescence can have a significant impact on the adolescent's psychosocial development. In particular, having cancer can affect the normal development of body image and self-concept, relationships with others, autonomy and sense of identity and life direction. Most adolescents with cancer cope very well. They have the resiliency to spring back and function despite sometimes adverse situations (Zeltzer, 1980). It appears that the parental fear of relapse and the need to protect the adolescent who has had cancer may be more psychologically disabling than the disease itself (Hustins & Kelly, 1990a).

Some adolescents with cancer may have significant psychosocial problems (Carr-Gregg & Hampson, 1986). Not only do they have to deal with the disruption to their lives in the adolescent years, but they must also contend with the uncertainty of a life-threatening illness (Bennett, 1984). Given the enormity of the problems that confront adolescents with cancer, it is not surprising that studies of adolescents with cancer reveal alarming rates of non-compliance, behavioural problems, severe anxiety, clinical depression (Kashami & Hakami, 1982), school phobia (Lansky, Lowman, Vats & Gyulay, 1976) and peer rejection (Carr-Gregg, 1986).

In the past two decades, we have seen a marked improvement in the treatment and survival of adolescents with cancer. For health care professionals such as nurses, this success has introduced a new challenge: To tailor the treatment interventions to address the health concerns of individuals who are just beginning independent lives. As the rates of childhood and adolescent survival increase, it is recognized that the invisible scars of medical treatment such as altered body image far exceed those which are visible. These psychological effects can be life-long, especially when initially experienced during a critical stage of the life span.

Increasingly effective forms of psychosocial nursing intervention to



Kathryn Hustins

facilitate adjustment and coping are that of oncology patient support groups (Heiney, Ruffin, Ettinger & Ettinger, 1988), parent support groups (Heffron, Bommelaire & Masters, 1973) as well as groups for siblings of patients with cancer (Cunningham, Betsa & Gross, 1981). Within recent years, there has been the emergence of support groups for adolescents with cancer (Carr-Gregg & Hampson, 1986; Heiney, Wells, Coleman, Swygert & Ruffin, 1990). This paper will present such a group for adolescents called Newfound Friends, describe its development, outline the purpose and goals, and present the group's format, membership and activities.

Development

Newfound Friends was established initially for adolescents who have survived cancer. The adolescents identified that they wanted a forum to support one another throughout their adolescent and young adulthood years. They wanted an opportunity to come together more frequently for support and companionship. In 1987, the nurse clinician in oncology at the Health Sciences Complex was contacted by the local Candlelighters Association to request assistance in organizing this adolescent support group. The nurse clinician solicited the assistance of a faculty member at Memorial University School of Nursing who had background in adolescent and group counselling to act as a co-facilitator. In the fall of 1987, they initiated a group meeting with three adolescents who had survived cancer. The group remained small during the first year as the members tried to encourage other adolescents with cancer to attend. It was not until the fall of 1989, when the group announced the production of a video, that more adolescents became interested and started to attend meetings on a regular basis. In the early years, the adolescents named the group Candles for Hope, but over time came to feel that the name was too closely associated with the Candlelighters Association and did not reflect the energetic enthusiasm of its young members. Thus in 1989, the name was changed to Newfound Friends with the hope that other groups across the country might pick up the idea (eg Nova Scotia Friends, Ontario Friends, British Columbia Friends). The group has grown over the past five years, with 10-12 regular members and an outreach membership of 100-125 members.

Purpose and goals

The purpose of the Newfound Friends group is to provide opportunities for adolescents with cancer to come together to discuss their problems and concerns. The hope is to promote positive

NEWFOUND FRIENDS: UN GROUPE DE SOUTIEN PSYCHOLOGIQUE POUR LES ADOLESCENTS QUI FONT FACE AU CANCER ET/OU ONT SURVÉCU À LA MALADIE

ABRÉGÉ

L'adolescence est une période de développement surtout marquée par les changements. L'expérience du cancer au cours de cette phase de la vie a souvent un impact sur le développement normal de l'image de son corps et de l'image de soi, sur les rapports qu'on entretient avec les autres, sur l'autonomie et le sens de l'identité, ainsi que sur la façon dont on oriente sa vie. "Newfound Friends" est un groupe de soutien pour les adolescents qui font face au cancer ou qui ont survécu à la maladie. La raison d'être du groupe est de promouvoir une santé sociale et psychologique positive. Cet article décrit les buts, les membres et le format de "Newfound Friends" ainsi que ses activités thérapeutiques. Ce genre de groupe pourrait aisément être organisé dans d'autres provinces par des infirmières qui soignent des adolescents ou de jeunes adultes faisant face au cancer.

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psychological and social health in adolescents who are coping with cancer, as well as to offer a support group for adolescents who have survived cancer. Although each person's cancer is unique, there are shared elements. The goals of the group are to: 1) facilitate healthy coping with the crisis of treatment and follow-up; 2) promote independence and self-responsibility and 3) share experiences, feelings and coping strategies with others. The goals direct the group's activities. The group can provide a forum where adolescents may resolve the crisis of treatment, normalize their concerns and fears, master the psychological and social skills of adolescence and go on to live productive lives. Some adolescents seek help from the group so they can get through the initial stages of treatment, while others have a few years of experience to share.

The first goal, facilitating healthy coping during the crisis of treatment, is achieved by group members sharing common feelings and concerns, problem solving, and facilitators encouraging school and social networks to decrease isolation. Some signs of difficulty coping with cancer are: A lack of joy and satisfaction with one's life, experiencing sad feelings and nagging feelings of withdrawal or depression. Some of these are a normal reaction when someone initially discovers he or she has cancer, but are disruptive when the person is unable to get on with life and establish new patterns of coping (Goldman and Tull, 1983).

The second goal, promoting independence and self-responsibility, is achieved by assisting the adolescents to complete the psychological and social skills of adolescence through social events and structured activities. Such activities involve planning and organizing events, presentations to the community, as well as the publication of the newsletter. Research findings indicate that returning to school, maintaining peer relations and becoming independent are difficult for the adolescent with cancer (Gavaghan & Roach, 1987). Because of long periods of hospitalization and treatment, they may not have been in social situations or had the opportunity to interact with peers. Parents are sometimes overprotective and limit the adolescent in his or her activities (Goldman & Tull, 1983).

The third goal, sharing experiences, feelings and coping strategies with one another, is achieved through group discussion with peers, interacting in social outings, and developing a sense of pride in accomplishments. To overcome successfully the challenges of dealing with a life-threatening diagnosis such as cancer, the adolescent needs to find meaning in the experience. He or she must set realistic goals for him or herself. Perhaps the most meaningful experience of all is to support other adolescents with cancer in treatment.

Membership and format

Newfound Friends was initially for adolescents between 14-21 years of age. As the members grew older than 21 years, they indicated a desire to stay with the group and so the age has extended. Registration is not required and adolescents may attend as they feel the need. The group has open membership and no registration fees. Funds are raised for special events to enable individual members to attend conferences and to publish a biannual newsletter. The group meets twice a month on Saturdays from 1400 - 1600 hours. The meeting place is Memorial University School of Nursing because, unlike a hospital, it is a neutral place. The nurse clinician and the nursing faculty member are the facilitators for the group.

Table One: Purpose and goals of Newfound Friends

Purpose

- Provide opportunities for adolescents with cancer to come together to discuss problems and concerns.

Goals

- Facilitate healthy coping with the crisis of treatment and follow-up.
- Promote independence and self-responsibility.
- Share experiences, feelings and coping strategies with others.

The format is informal and directed by the adolescents' concerns and needs. Meetings open with members giving an update on what is happening with their lives. Their news covers a wide range of topics from new boyfriends or girlfriends to the relapse or death of a member. There are no rules except for confidentiality and a willingness to share. The therapeutic value of the group meeting includes sharing of feelings and a sense of commonality (Yalom, 1985).

It has been documented that difficulties sometimes arise when a member dies or has a relapse (Heiney et al., 1990). We have seen this in our group. Group members are naturally devastated and experience a variety of emotions. Last year, a young adolescent male died after a lengthy battle with leukemia. Many members expressed concern regarding their own remission state and whether their cancer would return. A couple of members felt the need to seek reassurance from their physician. A meeting is held with the group facilitators and members to share their feelings and fears. The group members acknowledge their relationship and feelings for these members in their newsletter through poetry and sympathy letters. Some members also choose to attend the funeral of fellow members.

Activities

Activities are a mechanism for promoting group cohesion and recruiting new members as well as assisting the adolescents to become independent and self-responsible (Heiney et al. 1990). As the membership may range from the adolescent who has just begun treatment to the adolescent who is a long-term survivor, the group is structured so that the nature of the activities and events depend on the "stage" of the group. This helps to maximize the therapeutic benefits of group activity.

Mailing list

The list is a means of keeping in touch with outreach members. It originated with the summer camp participants and the local Candlelighters Association provided initial financial assistance. It lists each active member by name and address as well as resource persons and groups which are actively interested in the area of oncology. The list is updated each year so that active members can keep in touch with each other.

Two to three times a year, a newsletter is published. Content for the newsletter comes from group meetings. The group elects its own editor and all members including the facilitators contribute to the newsletter. Articles of interest such as "Ten Commandments for Human Relations", "Friends Forever", "Keeping Happy", "What is a Winner" are written by the individual group members. Also included are social activities such as bake sales, Christmas parties and winter outings, conference/workshop reports and humorous quotations which are used to stimulate interest. Announcements of upcoming events and a mailbox are included to encourage readers to write and join in. The newsletter serves the vital function of keeping members informed about each other and helps them to be part of the group even if they live at a distance. For some members, there are distance obstacles up to 80 miles. In turn, the newsletter helps the active members assume responsibility and a sense of pride in their accomplishments.

Archives

The group is presently developing an archive through a series of scrapbooks which include newsletters of the group, information

Table Two: Activities of Newfound Friends

Activities

- Mailing list
- Newsletter (2-3x year)
- Archives (Scrapbooks of Events, Conference Materials, Logo)
- Social/community events (Christmas and Valentine party, May picnic, Annual Health Fair, cancer workshops and conferences, radio and television interviews)
- Video production

brochures on the group, letters of acknowledgement and gratitude, photographs, newspaper clippings about the group and accomplishments of individual members. This activity provides the group members with a sense of connection with other members, group recognition and accomplishment. The logo for the group has undergone changes as a reflection of the change in the name of the group. The first logo was a candle and holder. With the new name of Newfound Friends came a new colourful logo which presents the image of a group of young people banded together in harmony and friendship.

Social events/community events

Social events include a Christmas party, Valentine party and May picnic as well as a craft and bake sale. Every year we participate in the Health Sciences Complex Annual Health Fair where members display posters created by themselves as well as share information on the group's activities and events with interested individuals. As well,



The Newfound Friends group helps adolescents deal with cancer.

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many of our members are invited to speak at cancer workshops and conferences. Members of the group have been featured on both radio and television programs.

Video production

In 1989, the adolescents decided that they wished to make a video they could share with other adolescents, school peers, teachers and health professionals on the concerns and problems of adolescents coping with cancer. With the assistance of the Health Sciences Medical Audio Visual Services, group members spent a year planning and making the video. The adolescents created the script themselves by focusing on five specific areas that they felt adolescents and families with newly-diagnosed cancer would need to know. The areas were: Problems encountered during treatment/hospitalization, feeling different, advice to give others, concerns regarding health and life, and dreams for the future.

The videotape "What Comes Next?" (Hustins & Kelly, 1990b) is a component of an educational learning program produced by the facilitators (Hustins & Kelly, 1990b) which contains instructional material to be used in conjunction with the video production. This video demonstrated the concerns, experiences, feelings and problems of adolescents coping with cancer. It serves as a lecturing tool in medical, nursing and other health care professional schools. The adolescents of Newfound Friends use the video as a tool when they are invited to conferences/workshops as speakers. The video premiered on May 6, 1990 to an audience of 100 friends, relatives and supporters. Plans are being made to market the video to other oncology groups across the country.

Summary

It is essential for professional nurses today to become involved in organizing and facilitating support groups such as Newfound Friends. Support groups are being recognized as an important clinical practice nursing intervention. As a facilitator of Newfound Friends, I have grown both professionally and personally. Such an experience has allowed me to understand some of the difficulties these young people face as they survive cancer. It has helped me also to recognize and appreciate the strength and endurance these young people possess to overcome their disabilities. As well, the adolescents through this support opportunity develop decision-making skills, positive self-esteem and independence. As nurses, we recognize that these adolescents sometimes appear mature well beyond their years. Yet when we look beneath the surface, we see small children who yearn for understanding and acceptance to be seen as whole, and affirmation that they have indeed survived cancer and are able to become productive members of society. ↓