

Beyond respite and activities . . . a message of solidarity

Evaluation of the In-Home Respite Program Phase II

Summary

**Suzanne Mongeau
Pauline Carignan
Manon Champagne
Marie-Claire Laurendeau
Stephen Liben**

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by

Suzanne Mongeau, Ph.D., École de Travail social, UQÀM

Pauline Carignan, MA Psych., research professional, UQÀM

Manon Champagne, MA Ed., doctoral intern, UQÀM

Marie-Claire Laurendeau, Ph.D., Institut national de Santé publique du Québec

Stephen Liben, M.D., Montreal Children's Hospital

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SUMMARY ¹

THE STUDY CONTEXT

This is an evaluative study of a respite program for families of children with life-threatening illness, many of whom require complex care. The In-Home Respite program was developed by The Lighthouse, Children and Families, an organization founded in 1999 by parents and professionals from pediatric health care facilities across Montreal. The respite program consists of recreational activities carried out by volunteers in the homes of the gravely ill children and their families. The Lighthouse is also working towards the establishment of a residential centre to better serve the respite needs of families caring for children with life-threatening illnesses.

OBJECTIVES OF THE PROGRAM

The overall objective of The Lighthouse's program is to offer both respite to parents and enjoyment to the sick children. The program's specific objectives are:

1. To provide families with time to re-energize;
2. To give seriously ill children access to recreational activities adapted to their condition and home environment;
3. To foster the involvement of siblings in the recreational activities;
4. To encourage families to actively participate in identifying needs and finding solutions (empowerment of families);
5. To provide volunteers with the necessary training support and development to enable them to assist the families;
6. To encourage volunteers to participate in improving services;
7. To develop partnerships with regional institutional and community resources.

OBJECTIVES OF THE STUDY

This study has two main objectives:

1. To conduct an in-depth analysis of the action process of The Lighthouse's In-Home Respite program;

¹ This summary is taken from a report entitled *Beyond respite and activities . . . a message of solidarity*. For more information contact Suzanne Mongeau, Université du Québec à Montréal, École de Travail social, Case postale 8888, Succursale Centre-Ville, Montréal, Québec, H3C 3P8; (514) 987-3000, extension 4991#; mongeau.suzanne@uqam.ca.

2. To analyze the personal development of the program's participants (fathers, mothers, sick children, siblings, volunteers) as a result of their participation in the program.

In order to meet the two main objectives described above the more specific goals are :

1. To describe the program's existing support and training practices;
2. To elicit perceptions of the various participants with regard to these support practices and to their own development;
3. To identify the factors that influenced the quality of the service provided;
4. To ascertain the level of satisfaction of parents and children with regard to the program;
5. To identify the existing or potential practices that contribute or could contribute to the empowerment of families;
6. To identify obstacles and facilitators to families feeling empowered;

METHODOLOGY

Approaches and strategies

A participatory approach was used for this study. Findings were periodically communicated to program managers and volunteers so that they could be integrated into the service. In addition, the main parties involved in the program contributed to the fine-tuning of the instruments used with the families and volunteers. A case-study strategy (Yin, 1994) was chosen for the research and The Lighthouse was the case study. A qualitative methodology was used to meet the research objective of gaining an in-depth understanding of a complex yet still little-known phenomenon. However, as suggested by Casebeer and Verhoef (1997), a quantitative methodology was also used to obtain a better evaluation of the changes observed.

Recruitment of families and volunteers

Families were recruited by The Lighthouse's staff. To obtain the participation of 24 families, 28 were contacted. In two-parent families, both parents were invited to participate in individual interviews. Thus, 37 parents (24 mothers and 13 fathers) participated in the first interview. This initial number of 37 parents was reduced to 26 at the time of the third contact with the families. Fifteen mothers and nine fathers responded to the full set of questions, while two mothers participated in an abbreviated interview, as they had had only a few volunteer visits. Short interviews were conducted with seven children who were well enough to respond (six sick children and one sibling who had had personal visits from a volunteer). Six other siblings were also interviewed. Fifty active or former volunteers also participated in the study. They were recruited with the assistance of The Lighthouse's coordinator of volunteers. In December 2002, all 16 volunteers with six months or more of experience in the program agreed to participate in individual interviews. Two discussion groups of volunteers were also created : the first at the very beginning of

the study, involving 27 volunteers who were already active or who were waiting to be matched with a family, and the second, 18 months later, involving 9 volunteers with at least three months' experience. Of the 26 volunteers who had dropped out of the program, 21 agreed to respond to a telephone interview.

Sources, treatment and data analysis

Several sources of information were used to collect the data for the study:

1. Individual interviews with mothers and fathers;
2. Individual interviews with seriously ill children and their siblings;
3. Individual and group interviews with volunteers;
4. Individual and group interviews with project managers;
5. Telephone interviews with professionals in a position to refer families to the program;
6. Consultation of written documents produced by The Lighthouse;
7. Informal observation and discussions;
8. Use of a quantitative questionnaire.

Semi-structured audio-recorded interviews with parents, severely sick children, siblings, volunteers, project managers and referring professionals provided the main sources of information. Verbatim transcripts were made of the individual interviews with parents and volunteers. A qualitative content-analysis method was used for all interviews (L'Écuyer, 1987). Written documents were also treated systematically using qualitative methods based on the reduction or condensation of the data (Corbin, 1986a, Corbin, 1986b; Poisson, 1991). The data obtained using the closed questionnaire were treated quantitatively using descriptive statistics. The value assigned to the data collected was verified using the method of triangulation of different data sources.

RESULTS

First, the families' living conditions are described, as they provide a picture of the parents' needs for support and respite as well as a better understanding of their perceptions of the effects of the program. The main results of the evaluation of the program are then presented.

The findings pertaining to the families' situations reveal that, in general, the medical condition of the sick children is very serious. The majority of the children participating in the In-Home Respite program suffer from degenerative diseases with little or no hope of cure. These children suffer from severe or total loss of autonomy. A few of the participants have forms of cancer for which there is some hope of a cure. A large number of the children receive complex care. The children's serious illness has important repercussions on the overall living conditions of their families as it creates major physical, emotional, economic and professional difficulties, as well as affecting the general organization of the

household. A large percentage of these families suffer major reductions in income and a number of parents, mainly mothers, have difficulty maintaining a work life.

The families' situations reveal the existence of many shortcomings in the availability and organization of support services. Resources for seriously ill children and their families are poorly adapted, insufficient, or even non-existent. Parents do not know where or how to obtain support and they see an urgent need for a centralized organization that can provide them with information on available resources. The research findings indicate that the more serious the child's illness, the more difficult it is for parents to obtain assistance from their relatives and friends or from government organizations. The parents deplore the unfairness of the current system, which provides even less government financial support to those who care for their sick children at home than to foster families. The parents made a number of proposals aimed at improving the support they receive. They suggested that government assistance be directed towards family support, to help them care adequately for their children. Parents also expressed their hope that legislation and social policies will be put into place to support and protect their rights as workers. In addition, parents highlighted their need for access to various types of resources offered by volunteers and professionals both at home and in a residential care facility.

With regard to the evaluation of the In-Home Respite program, two main themes emerged from the responses of the various parties involved: 1) The program's strength and relevance; 2) The program's complexity and fragility. The next section presents the various elements contributing to these characteristics.

The strength and relevance of the program

- Enjoyment for the child . . . respite for the parents

One of the program's strengths is that it allows sick children to enjoy themselves while they discover, develop and obtain recognition for their creativity. This enjoyment helps the child to go on living and to find a temporary escape from his medical condition. The program gives the children the opportunity to exist outside their illness. They look forward to their volunteers' visits as specific times for enjoyable activities, and this anticipation helps to reinforce their will to live. The program also responds to one of the important needs of the child and the family, "to be seen as a *normal* child and a *normal* family [...] in spite of their 'abnormal' situation" (Ernault, 1994: 394).

The model adopted by The Lighthouse has positive effects not only for the sick child but also for the parents who benefit from the respite provided. The program's design corresponds to the parents' idea of respite, by giving them the peace of mind that comes from seeing their children interacting happily with volunteers.

- An organization that fosters empowerment

Another of the program's strengths is that it fosters the empowerment of families. The results obtained using both the qualitative and quantitative methods reveal that listening to parents in order to better understand and respond to their needs constitutes one of the strong points of the In-Home Respite program. The mothers say that they feel less alone with their

problems thanks to the sympathetic ear offered by The Lighthouse's staff. They also affirm that the staff members take their views into consideration and help them to identify their respite needs. In addition, The Lighthouse regularly consults parents on the organization of future services or new projects or on improvements to the existing program. Parents' participation in internal surveys or evaluative research also makes them feel that their opinion counts reinforcing feelings of control and power.

The findings also show that The Lighthouse is receptive to parents' choices. It offers families "à la carte" services, adapting its support to their individual needs. Factors contributing to a strong feeling of satisfaction on the part of the parents are the organizational structure, which they perceive as simple, as well as the opportunity to choose the days and schedules of their volunteer visits. Overall, The Lighthouse is seen as a flexible resource that is able to adapt to each family's needs.

The Lighthouse's managers encourage and support the participation of parents on the organization's committees. However, the majority of parents pointed out that their situation as caregivers does not allow them to become actively involved in these activities. To better inform the parents of sick children, The Lighthouse has recently hired one of the mothers in the program to develop and write a resource guide, with a view to increasing the feeling of empowerment on the part of the families concerned.

Finally, The Lighthouse contributes to the consciousness-raising process by using the media to make the public aware of the living conditions of the parents of sick children and by ensuring public recognition of their role as natural caregivers.

- A message of solidarity and social recognition

The explicit objective of the In-Home Respite program is to provide both enjoyment to the sick child and respite to the parents. However, the data collected strongly indicate that another type of message, just as important as the concrete offer of respite, is implicit for the parents and children in the program. This message is one of solidarity and social recognition, and is perceived by parents as another important strength of the program.

This message is communicated and understood through the significant social bonds that are formed between the volunteers and the families. Indeed, parents feel that the volunteers truly recognize their special situation. While parents find it very difficult to make their condition understood among their relatives and friends, they feel that the volunteers quickly grasp its complexity. Indeed, the volunteers become privileged observers of the families' daily lives. The fact that volunteers choose to visit their sick child and offer this kind of support without financial compensation is interpreted by parents as a message of solidarity and social recognition. In the parents' eyes, the volunteers represent not only The Lighthouse, but also society as a whole. Volunteers are seen as a link to the outside world and as the embodiment of the community's support.

This feeling of solidarity naturally allows parents to see themselves as less isolated and socially marginalized. Thanks to the volunteers' visits, parents whose arduous living conditions understandably give rise to feelings of unfairness, and sometimes even of

despair, come to the realization that what happens to them really is important to other people. In short, the volunteers' visits counterbalance the perceptions of unfairness and enable some parents to regain hope that society has not completely forgotten them.

Volunteers provide social recognition not only to the parents but also to the children. Parents want their children to be recognized for all their achievements, even those that may seem unimportant to healthy individuals. For these parents, it is not performance in and of itself that matters, but rather what their child is still able to do. According to parents volunteers see their child for what he is and not for what he "should be."

Another source of social recognition for parents is The Lighthouse's presence in the media. The Lighthouse has frequently been covered by periodicals, scientific conferences and newspapers, as well as on radio and television. On each occasion, testimonials from parents were included to increase awareness of their living conditions and their role as caregivers. These activities have allowed parents to obtain public social recognition of their difficult situation.

However, while The Lighthouse's volunteers and managers are aware of the social support that their actions can provide for families, they know that they are still only partially responding to the families' needs in this regard. For example, in our research cohort, mothers use the respite offered to attend to their daily household tasks, rather than resting or taking the time to enjoy a leisure activity. It is for this reason that structural changes to the services are necessary for the improvement of families' living conditions.

- Accompaniment, not intervention

The volunteers' role is not one of professional intervention, but rather of accompaniment. Parents see this as another of the program's strong points. Volunteers do not view the families with a critical eye, rather they conform to the habits, rules, roles, observances and belief systems of the families, which may mean putting aside their own habits and beliefs. Their objective is not to change the families; rather, they try to adapt their support as closely as possible to the wishes of the parents and the children. The relationship forged between the volunteers and the families is not one of power, and this is one of the reasons for the depth of the social bonds that form between them.

The support relationship established between the volunteers and the families is indicative of values that run counter to those of our performance-oriented society, where productivity, efficiency, competition, profitability and individualism are the norm.

- A program characterized by openness

One of the objectives of The Lighthouse is to develop partnerships. Indeed, the summary of the partnerships created over the past two years is very positive, both in quantity and in quality. While a great deal of communication work remains to be done and must be maintained on an ongoing basis, The Lighthouse has nonetheless succeeded in creating a network of referring professionals from pediatric hospitals, community organizations and, more recently, CLSCs. In addition, collaborations between The Lighthouse and various establishments have led to a number of successful activities. For example, The Lighthouse

has welcomed interns from educational institutions, and representatives of other organizations have participated in its committees, in the organization of family days and in the training of volunteers. Conversely, some of The Lighthouse's employees have participated in various groups dealing with volunteer issues. All these partnerships have been developed in spite of the fact that The Lighthouse has quite a small team that has undergone numerous personnel changes over the past two years.

The organization's openness has also been evident with respect to its own services. Despite the families' high level of satisfaction with the In-Home Respite program, The Lighthouse's managers, board members and volunteers have shown an ongoing concern for the families' other needs that are not met by the current program. That is why they are continuing to work towards the creation of other respite options for families of children with life-threatening illnesses, such as the establishment of a residential care facility.

The program's complexity: an aspect to be maintained

The organization's employees mentioned the program's complexity, while the statements of the parents and volunteers made no reference to this aspect of the program. In fact, in their evaluation, the parents underlined the uncomplicated structure of The Lighthouse. Thus, the complexity and weight of The Lighthouse's mission appear to be borne entirely by its program managers. This is one of the factors contributing to the very high satisfaction rate on the part of the families.

The elements that constitute the program's strength are also responsible for its complexity; this finding emphasizes the importance of preserving this complexity if the richness of the program is to be maintained.

- Behind the program's simplicity and flexibility . . . some very complex logistics

When a family is referred to The Lighthouse, several actions are taken, some of which are quite complex. The evaluation of the families' eligibility is a delicate process in itself. A great deal of flexibility is required in interpreting the eligibility criteria. Moreover, with certain families, it is difficult to broach the subject of the life-threatening nature of their child's illness, which is in fact one of the eligibility criteria. Meeting the specific and individual needs of each family is also a challenge, because each case must be constructed from the beginning. The matching of families with volunteers is another complex operation, given the size of the territory to be covered and the difficulty in maintaining a balance between the families' requirements and the availability of volunteers.

In short, behind the program's deceptively simple appearance there are some very complex logistics. However, it is important to maintain the complexity of the "à la carte" approach, which is an important factor in the families' satisfaction with the program.

- The possibility of losing focus

Because of the extremely arduous living conditions of the participating families and the immensity of their needs, there may be a tendency to want to become a saviour for each family. A shift of focus, toward evaluation or therapeutic intervention, can occur, given the painful nature of the situations encountered. Maintaining a balance between the preservation of The Lighthouse's mission and its adaptation to the needs of each family is therefore a complex task. That is why it is important for the team to have frequent informal discussions and consult the Care Committee of The Lighthouse from time to time.

- Contradictory tensions inherent in the volunteer action

Several contradictory tensions arise out of the complex relationship between the child-family and volunteer. The statements of the volunteers reveal that, in providing support to a seriously ill child and his family, a volunteer must be ready to create a significant bond and to experience a certain degree of proximity to the child, parents and siblings. The volunteer cannot remain "an outsider" within the family without jeopardizing the success of the relationship. The bond that is established, whether it is described as one of friendship or as something more akin to a family relationship, must be one of real convergence. As there is normally only one volunteer per family, the exclusive nature of the bond definitely contributes to the deepening of the relationship. The volunteer must be able to establish the right degree of closeness, so that convergence and detachment can coexist. The boundary between being close to the family and being an outsider will never be very clear or solid, and it would be inappropriate to try to change this. This complexity seems to be essential to the relationship, although there is sometimes a temptation to try to eliminate it. The coordinators of the volunteer service must take this complexity into account in their instructions to the volunteers. Indeed, it appears to be of the utmost importance not to unduly restrict the development of attachments, because limiting the quality of the bonds can result in higher volunteer turnover and a lower degree of satisfaction for all concerned: parents, children, volunteers and program managers.

Finding a balance between freedom and restraint is also very complex. From the volunteers' statements, it is clear that freedom is important to them. For some, it is this feeling of freedom that allows their relationship with the family to endure over time. However, at the same time, the staff of the Lighthouse must grapple with concerns about risk management. In some respects, The Lighthouse tends toward a restrictive approach, while some volunteers would like to have even more latitude. Here again, The Lighthouse must find a way to take into account the volunteers' need for freedom, while maintaining certain points of reference with regard to its operating rules. The managers of The Lighthouse are also dealing with volunteers of a new type; they are younger, often working or studying full time, and their motivations that are not purely altruistic because their own personal goals and needs are more strongly affirmed than in the past. Most of these volunteers reduce the duration of their commitment so that they can be involved in different types of volunteer work in various locations. The Lighthouse must adjust to this new reality and find ways to facilitate the recruitment of volunteers while responding to the needs of the families.

Another dilemma is that volunteers must learn to deal with the child's illness while maintaining their interest in him as an individual apart from his medical condition. They must provide enjoyment for the child while remaining sensitive to his suffering. In practical terms, the management of this type of tension is very complex. On the one hand, the volunteers must take care not to overlook the suffering of the child and his family and become overly active, and on the other hand they must not let themselves become overwhelmed and paralysed by that suffering, at the risk of not being able to play, create and have fun.

The program's fragility: a challenge to be met

The program's fragility is largely due to the constant quest for funds, an ever-present source of stress for all the employees of The Lighthouse. There is no doubt that the program would benefit from the attenuation of this need for funds. The Lighthouse's mission is clearly justified, and a substantial infusion of government funds would facilitate the financing of the organization. Nonetheless, despite the lack of financial resources, The Lighthouse has succeeded in becoming a significant and relevant player in the provision of support to families. However, it is the employees, not the families, who appear to have paid the price. The personnel hired by The Lighthouse must work long hours under very uncertain conditions. Moreover, it is not easy to find people with the training required to fill the roles required by The Lighthouse.

RECOMMENDATIONS

A number of recommendations aimed at offering real support to the families of children with life-threatening illnesses have come out of the study's findings. The description of the situation of families with seriously ill children shows the need to rethink the organization and nature of the services as well as the support policies, in order to provide real improvement of the living conditions of these families. They should be able to benefit from an integrated support model, with a single organization that can offer a full range of respite options, both at home and in a residential care facility, including support from volunteers and professionals. This centralized organization would also inform parents of the resources available, thus sparing them burden of coordination and searching for resources on their own.

Collective actions should also be undertaken. For example, parents of seriously ill children should ideally be represented by coalitions of caregivers, so that their rights can be better known and defended. In addition, because caregiving is largely invisible and not highly valued by society, it is important that The Lighthouse continue to use the media to inform the public and decision-makers of the needs of caregiving families.

Finally, with specific reference to the In-Home Respite program evaluated by this study, it would be preferable for the organization to continue to deal with the complexity of its implementation, rather than giving in to the temptation to eliminate this aspect. To this end, in the coming months, the organization should reflect on ways to establish the ideal rhythm that will allow it to offer personalized support to families while maintaining a structure that is perceived by the parents as flexible and uncomplicated.

