Give them a break

A study of families' perceptions of the supports available in the community for families with a child with a life-threatening illness

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The effectiveness of current support services for families who have a child with a progressive life-threatening illness seems to be a frequently overlooked issue. This paper, which is based on the findings of a recently conducted study, attempts to elucidate the critical issues in supporting this unique group of families. The study examined the perceptions of families regarding the value and effectiveness of the social supports available in the community for families caring for a child with a life-threatening illness in Victoria. Attention has been drawn to perceived gaps in support for these families. Also considered is the effectiveness of supports available for bereaved families who have lost children with life-threatening illnesses. The study was based on information provided by families who had been involved with a family support agency known as Very Special Kids.

PRESENT STUDY IN CONTEXT

The death of a child is undoubtedly one of the most painful and distressing tragedies that can beset any family. Fortunately, reductions in prenatal and childhood mortality rates have resulted in this occurrence becoming less frequent. However, this decrease has made the situation more exceptional, and in a sense, more difficult to cope with. Families tend to have high expectations of a successful, normal birth and healthy children, and the focus of medicine has become more intensive, technological and hospital-based. Consequently, both professionals and community workers have become less accustomed to supporting families whose children die or are suffering from a potentially fatal illness.

Research has demonstrated that the situation for children who have a progressive life-threatening illness and their families differs significantly from that of adults in several crucial ways. Fortunately, in most communities, dying children form only a small group of patients. However it also means that programs exclusively for these children are difficult to establish and support financially. This, along with the tendency to continue aggressive medical treatment to the end, may also help explain why there are so few programs especially designed for children with a progressive life-threatening illness. Compared to adult patients, the population of patients ranging in age from birth to eighteen years has greater variations in physical size, developmental levels, medical conditions and disabilities. It is also characterised by a wider scope of interests and communication abilities. There is also greater diversity in diagnosis among terminally ill children than for adults. This diversity requires a greater range of specialised services and skills than are required for adult programs.

The path of the major progressive life-threatening diseases of children is also distinctly different. Many of these children are severely incapacitated over a long period. This places a huge burden on their parents, siblings and other carers. Consequently, there is a great need to provide long-term support and periodic respite care for these children and their families.

Family support is an extremely important part of paediatric palliative care (Wilson 1988). Families generally suffer the death of a child more severely than that of an adult. Fischoff and O'Brien (1976) have pointed out that: 'The parents feel the loss of the child as if they have lost part of themselves, which, indeed, they have'. Research has also demonstrated that the length of bereavement following the death of a child is generally longer than that following the death of an adult. In adult programs, families are usually supported for a year after death. In contrast, in the case of death of a child,

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Corr, Martinson and Dyer (1985) found that more than one-fifth of families in their study reported that their most intense grief had not ended two years after the child's death. For another one-quarter, the most intense grief lasted for twelve to eighteen months. It also seems that sibling bereavement continues even longer than bereavement in respect to the death of a parent.

Up to now most support services for families who have a child with a progressive life-threatening illness have been provided by a limited number of dedicated public and non-government organisations. Meanwhile, clinical and related aspects of palliative care for children are usually provided by hospital staff in a hospital setting. The degree of non-clinical support varies by condition. Usually, most of the family support comes from the few illness-specific organisations and support groups that exist in the community.

The services provided through the hospitals are reinforced by a network of community-based support services. These can include Specific Home Help as provided by the local municipal councils, and clinical care, as provided by the Royal District Nursing Service. Support and counselling are also provided by a range of illness-specific organisations such as Canteen (for teenagers with cancer). *Very Special Kids*, a support organisation specifically for families with a child with a life-threatening illness, was formed in 1985. Prior to this, there was no facility which acted as a focal point for the provision of non-hospital based support services for families who have a child with a progressive life-threatening illness, and that was consistent with a family-centred approach.

Incidence of children with life-threatening illnesses in Victoria

Establishing the incidence of children with life-threatening illnesses in Victoria is a difficult task. Definitions of what is meant by *a life-threatening illness* lack consistency. Furthermore, there are no available figures on the incidence of children with life-threatening illnesses at any one time or over the course of a twelve-month period. Hence, the extent of the problem can only be indicated by examining annual figures of child deaths resulting from progressive life-threatening illnesses. The Prenatal Unit of the Department of Human Services records data on all infant and child deaths. Information is obtained from post-mortem reports, hospital records, death certificates and coroners' reports. According to the most recently available figures (1993), 209 children died as a result of cancers, acquired conditions, congenital malformations and birth defects in that particular year. Of these, 81.3% of the children were more than twelve-months old. This figure excludes child deaths resulting from accidents, cot death, non-accidental trauma or suicide. It also omits the multitude of families who are currently caring for a child (or in some cases, several children) with life-threatening illnesses. Also excluded is the multitude of families in desperate need of support because they are grieving the loss of a child with life-threatening illness.

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Literature review

The sphere of family satisfaction with available support options is still relatively under-researched. Research specifically on support needs of families who have (or have lost) a child with a progressive life-threatening illness is even scarcer – particularly the extent to which families receive the kinds of supports they feel are needed. This issue is a crucial one which is often overlooked. Other essential questions concern the effectiveness of currently available bereavement support programs.

Recognising and supporting the family's role means evaluating whether attitudes, policies and practices address the immediate long-term needs of the total family, rather than just the current needs of the child. Combined with increasing emphasis on the provision of family-centred care (Shelton et al 1987), the commitment to service is expanding to include support for the family's emotional, educational, physical and social needs (Flynn & McCollum 1989).

Clearly, the amount of emotional and physical stress faced by families who have a child with a progressive life-threatening illness is extreme. Additional stresses may result from logistics and expenses related to travel to and from hospital, sacrifice of employment, and child-care for siblings at home during parents' hospital visits. Increased financial burden may add to the acute emotional and physical stress that the family already faces. Family-centred care involves identifying a family's concerns, priorities and resources and creating a match between family-identified needs and strengths and supportive intervention strategies (Flynn & McCollum, 1993).

The provision of family-centred care becomes even more challenging when the family resides in a rural region. Families living in isolated rural regions may have a limited social network and long distances to travel between home and community resources or hospital. In addition, the financial burden may be increased due to cost of transportation to and from the hospital, overnight lodging, and extended child-care. The potential additional stresses for families living in rural areas dictate rethinking current policies and practices to provide family-centred care (Flynn & McCollum 1993).

Although the capacity of support for reducing stress has been well researched, there has been minimal attention directed towards families' opinions regarding the importance of various forms of support. In 1993, Flynn and McCollum made an attempt to study parents' opinions about the types and sources of formal family support available during their child's hospitalisation. The researchers also examined the perceived adequacy of formal support and gaps in services. Their study focused on families who had received services in a major regional hospital that provides neonatal intensive care. They found that parents need both formal and informal supports during the period of their infant's hospitalisation. However, their study gave minimal attention to the particular needs of families who have (or have lost) a child with a progressive life-threatening illness.

To uphold a family-centred approach in the care of terminally ill patients and, in particular, that of children, a precise and systematic assessment of supports needed for their families from the viewpoint of the families themselves, is clearly warranted. This study attempts to address this need.

METHODOLOGY

A mail survey was the main research instrument used to gather information. Specially designed questionnaires were posted to 232 families who used some form of *Very Special Kids* supports during 1995. The research focused on parental knowledge and satisfaction with support provision both within *Very Special Kids* as well as outside the organisation

In order to incorporate all relevant issues, it was necessary to divide the families into the following two groups and to send separate questionnaires to each of these groups:

- families with children with progressive life-threatening illnesses whose children were still living. For the purpose of the survey, these families were referred to as 'non-bereaved families'. This involved 176 families; and
- families with children with progressive life-threatening illnesses whose children were no longer alive. For the purpose of the survey, these families were referred to as 'bereaved families'. This involved 56 families.

A response rate of 69.4% was achieved. Given the nature of the study group (ie, families who are caring for, or have recently lost a child with a terminal illness), and given the sensitive and highly volatile situation of most of these families, this response rate was considered highly satisfactory.

The mail survey method of data collection, with anonymity of respondents, was used because of its high ability to achieve confidentiality. This meant that families would be likely to respond more honestly. However, the privacy afforded by this method also meant that it was impossible to verify information with other sources. In addition, it was not possible to compare non-respondents with respondents. Therefore, it cannot be ruled out that families who did not respond may have different opinions from those who did respond. Fortunately, these differences are somewhat offset by the high response rate to the survey.

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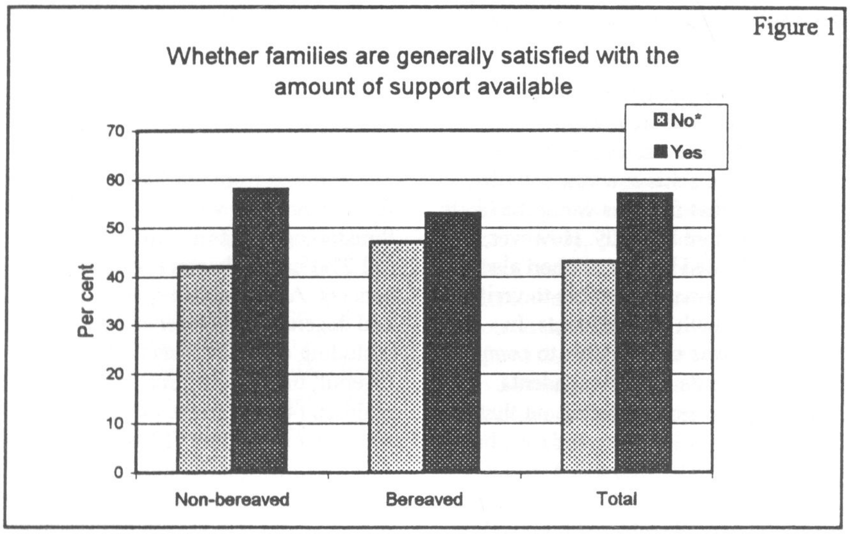
The study examined the perceptions of families who were part of *Very Special Kids* and had used its supports. It was therefore not possible to ascertain from the findings of the survey whether the opinions about supports available for families who have a child with a progressive life-threatening illness were typical of all families in the community who have (or have lost) a child with a progressive life-threatening illness, and not just representative of those involved with *Very Special Kids*. It is quite likely that families who had not come across *Very Special Kids* supports may feel even more vulnerable to breakdown and in greater need of support, than those who had. A separate survey would have to be undertaken to verify this.

The children from families who were in the survey had a wide range of life-threatening illnesses. About half (52.2%) had leukaemia or other cancers. A further one-quarter (26.1%) had degenerative or genetic conditions, including cystic fibrosis (9.3%). Overall, the highest proportion of children (40.1%) were in the secondary-school age grouping (12 years or older). Just over one-quarter (28.7%) were primary school-age children (6-12 years of age) and nearly one-third (31.2%) were babies and pre-schoolers (up to 6 years of age). More than three-quarters (79%) of the families were two-parent families, while about one-sixth (16%) were single-parent families. Only about one-third (33.5%) of the families (irrespective of their bereavement status) came from outside the Melbourne metropolitan area of Victoria.

ANALYSIS AND ISSUES OF CONCERN

This study confirms that *Very Special Kids* is a significant and rapidly expanding component of the support system for families who have a child with a life-threatening illness. This organisation has supported nearly 500 families since its inception. In 1995 alone, *Very Special Kids* supported approximately 250 families who came from both the metropolitan as well as the non-metropolitan areas (one-third). The majority of these families were non-bereaved families (ie, those whose children were still alive). Nonetheless, as many as one-third were bereaved families (ie, families who had already lost a child due to a life-threatening illness). Over the year, the organisation also managed over 100 volunteers who have supported families both at home or while their child was in hospital, conducted several camps and also enabled numerous families to have a holiday in the country. *Very Special Kids* has also provided families with a variety of other forms of emotional and social support and respite care. These supports have been of great value in relieving emotional strain; assisting in

Figure 1



emergencies; allowing families to attend to other family or social-recreational needs; and more generally, helping to normalise their family life as much as possible.

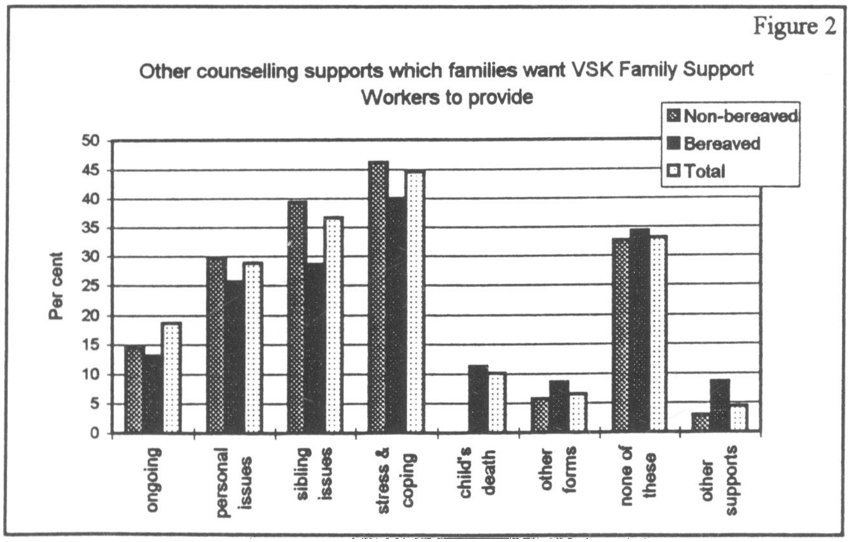
The specific support most used by non-bereaved families was the service of a home volunteer. More than half (57.6%) used this support during the year. Camps (24.2%), holidays (22.7%) and social activities (19.7%) were also utilised.

The support most used by bereaved families was Family Support Worker counselling. Over half (52.2%) of these families who used specific bereavement supports drew on this support. The majority of these families resided in the metropolitan area.

Satisfaction with the type of supports provided by *Very Special Kids* seemed generally high (83.8%) and most feedback was positive. Nearly two-thirds of the families have combined the supports they were receiving from *Very Special Kids* with others available in the community. Overall, most families felt that *Very Special Kids* supports and assistance combined well with, and did not duplicate, those available in the community.

The study's findings indicate that increasing recognition is being directed towards the importance of supporting families of children with life-threatening illnesses. Undoubtedly, the supports currently provided by *Very Special Kids* have enormous value for the families involved. Nonetheless, numerous concerns and problems exist about supports generally in the community for families who have a child with a life-threatening illness.

Figure 2



Nearly half the families (43.4%) said that they were **not** satisfied with what is currently available in the community. The following concerns were brought to attention:

Lack of information regarding supports available in the community for families who have a child with a life-threatening illness

The lack and/or inadequacy of information available to families about what support the community offers, seems to be a major problem – especially given that more than half of the families felt inadequately informed about what was available. Information areas most frequently found to be lacking or inadequate concerned:

- support groups for a specific illness;
- agencies providing advocacy for such families;
- support agencies which could help with siblings; and
- supports available for families living in the non-metropolitan area.

Scarcity of supports in the community for families who have a child with a life-threatening illness

Evidence indicates that a substantial number of families feel that the amount of support they are receiving is far from adequate. Nearly half (43.4%) were dissatisfied with what is currently available in the community. Bereaved families, in particular, seemed dissatisfied: nearly half had experienced problems when using supports in the community, and three-quarters felt that there were other supports needed.

Overall, there were numerous important supports which families felt were needed, but lacking in the community, to support families who have a child with a life-threatening illness. These included:

- **Counselling type supports**
  The need for counselling has been recognised as a most vital form of support, both for families caring for a child with a life-threatening illness and also for families grieving the loss of children. Yet, despite this recognition, counselling options seem to be scarce. Two-thirds of the families who responded to this question felt that at least one of the major counselling options that were

suggested by the questionnaire was inadequately covered in the community. The following were most frequently marked as lacking: stress and coping counselling; sibling counselling issues; personal discussion regarding emotional issues; and regular ongoing counselling.

- **Other supports inadequately covered in the community**
  Besides counselling type supports, families felt certain other supports were lacking or poorly covered in the community. Overall, only one-eighth of all the families did not see a gap in the provision of any of the options mentioned in the survey. The following supports appeared to be of greatest need:
  - o **a resource booklet providing information about what is available in the community** (given particular mention by families living in the non-metropolitan area);
  - o **the provision of some type of resource link with other families with children with the same condition** (given particular mention by bereaved families and families living in the non-metropolitan area);
  - o **a sibling support group;**
  - o **information on how to use the hospital system** (given particular mention by families living in the non-metropolitan area);
  - o **a father support group** (given particular mention by bereaved families and families living in the non-metropolitan area); and
  - o **a support group for grandparents** (given particular mention by bereaved families).

It is of particular concern that about three-quarters of the families felt that at least two of the options mentioned were inadequately covered in the community and that just over one-quarter (26.8%) of the non-bereaved families saw as many as four or more of the options as ones that were needed. Not surprisingly, most of these families had said they had encountered major problems using supports and assistance in the general community.

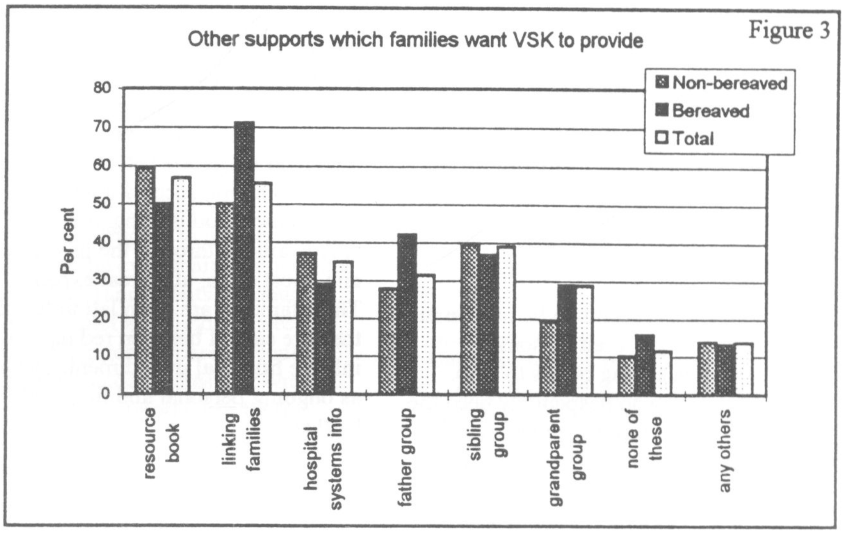


Figure 3

Other supports which families want VSK to provide

In trying to identify a family's resource requirements in addition to those supports already discussed, attention needs to be drawn to certain other greatly needed supports which families feel are lacking in the community. These include the following:

- lack of adequate respite care facilities for families who have a child with a life-threatening illness. This seems to be an area of particular need. Amongst the diversity of problems and concerns that were expressed in this respect, the following stood out:
  - o inadequately trained and/or inexperienced in-home helpers;
  - o insufficient in-home respite;
  - o lack of vacancies in respite care facilities;
  - o inability of respite care facilities to cope with highly medically fragile children;
  - o inability of respite care facilities to cater for children other than children specifically with disabilities; and
  - o inability of adult respite care facilities to cater adequately for palliative care of children.
- lack of guidance during child's illness: 'Families sometimes lack guidance during child's illness and are left to flounder if they appear to be coping'.
- lack of ongoing support especially with respect to bereavement support. Most accessible bereavement supports for families who have a child with a life-threatening illness are only available on a short-term basis. This is believed to be partly because, as one family put it: 'Grief is often perceived as being a short-term thing by the community'. The tendency of many supports to withdraw after the death of the child is also a concern that needs further attention.
- no immediate support on diagnosis. More information is needed about how to cope with relevant conditions.
- poor coordination between different areas of support provision: 'Impossible to obtain full support from one source'. More support coordination is needed particularly for:
  - o families with more than one sick child; and
  - o families caring for children who are ill but do not have intellectual disabilities.

Inadequate supports for families living in the non-metropolitan area

Families who have a child with a life-threatening illness who are living in the non-metropolitan area have a major problem in accessing supports. These families are experiencing tremendous difficulties, especially in the following areas:

- lack of knowledge of support services and support groups;
- support availability, fewer accessible support services, reduced access to in-home support and limited access to

other families with children with similar conditions;

- limited range of bereavement support; and
- lack of flexibility in the allocation of resources at the regional level to meet local needs.

Inadequate community education

Further attention seems to be needed in alleviating the guilt felt by some families when asking others to help. Many families who desperately need the supports still feel guilty, or are made to feel guilty about using them. This also draws attention to the problem of judgmental supports: 'Some places make you feel guilty – especially if your child is in remission'; and: 'Service is grudgingly provided'. Such problems can have serious broader implications. At worst, they can result in families rejecting family support services or relegating them into being used only as a last resort, rather than serving their purpose as forms of stress reduction and ongoing support.

Further attention also needs to be drawn towards educating the general community about understanding the support requirements of families who have a child with a life-threatening illness. This form of preventative work needs to be seen as a major component of the community support for families who have a child with a life-threatening illness. Families indicated that there is a need to direct more attention towards educating the school community about children with life-threatening illnesses.

Costs of obtaining specialised supports

The financial burden faced by many families who have a child with a life-threatening illness is known to be often extraordinary. Exceptional costs for these families include specialised equipment, assistive devices, child-care and often transportation and accommodation for out-of-town appointments. Families also mentioned the high costs of obtaining supports such as psychological counselling for the child, the cost of home care of the terminally ill child, and the high costs of intensive support during crisis time: 'It is difficult to get support during crisis without having to pay for it'. Dollars are rarely attached to the child but rather to individual agencies and programs. Some support programs pay only a portion of costs or put a ceiling on costs covered. Others insist on a particular diagnosis before funding, whereas others, such as intensive bereavement counselling, are mainly only available through the private sector and, most often, at a great expense. Thus, families are often left to feel that they are caught between red tape and infinite financial impediments as well as ongoing personal and financial battles.

The study indicates that recognition of the importance of supporting families of children with special needs is increasing. Nonetheless, there is an urgent need to re-examine the adequacy of supports available specifically for families who have (or have lost) a child with a progressive life-threatening illness in Victoria.

CONCLUSIONS

Children with life-threatening illnesses and their families present a multiplicity of needs, with many possibly benefiting from a variety of disciplines, programs and agencies. However, the current system of supports for children and their families seems to lack clear formulation. Most supports and programs have developed as specialised ones to assist families with different needs. This specialisation has tended to fragment support delivery and to create a variety of separate funding eligibility criteria and funding streams for supports. Each of these have claimed some, but not exclusive, responsibility for providing a part of what is required by children with life-threatening illnesses and their families. Many of these families, however, do not fit into specific categories, and their needs are often multiple and interdependent. Hence many systems are currently serving the same families, while others are totally excluding families who have nowhere else to go. Often supports that do exist become inappropriately used due to either absence or lack of availability of other more appropriate ones.

The question of how family supports are to be delivered is of critical significance both for families who have a child with a life-threatening illness and for policy development. The degree to which families are empowered to exercise choice in the amount, type, source and use of family support is particularly crucial in this respect.

This study has attempted to address the lack of attention that has been given to exploring the support needs of families who have a child with a progressive life-threatening illness. Based on families' perceptions, the study indicates that there are major restrictions in the way certain supports are provided for these families. Although it is apparent that family support has enabled most families to cope more effectively with their child with a life-threatening illness, it has not enabled all to do so to the same extent.

This study has confirmed that the majority of *Very Special Kids* families feel positively supported by the organisation. However, it has identified that, generally, certain greatly needed supports within the community for families who have a child with a life-threatening illness are not always available. Most of the supports available were regarded as suitable, but inadequate, to meet the needs of nearly half the families in the study. In particular, families who have children who are severely medically fragile were frequently the most needy and the least served.

In relation to supports within the wider community, it is of concern that more than half of the families were poorly informed about the existence of the existing major family supports. In addition, many families encountered problems with respect to lack of availability of respite care and counselling supports. A large proportion of families encountered problems to do with either long waiting periods, location, or distance, and a noticeable number also felt that other restrictions also existed and that some of the available family supports needed improvement. In addition, many of those families who were not using family support, responded that current supports were unsuitable or inappropriate because they were inaccessible.

Often, the family has little or no experience in dealing with the maze of social and health services. Putting services and funding together in bits and pieces is an extremely difficult task for the family, given the variety of criteria that are used to determine service and funding eligibility.

The study indicates that recognition of the importance of supporting families of children with special needs is increasing. Nonetheless, there is an urgent need to re-examine the adequacy of supports available specifically for families who have (or have lost) a child with a progressive life-threatening illness in Victoria.

Care for children with life-threatening illnesses requires greater financial and program supports. Currently, responsibility for supporting children with life-threatening illnesses and their families has not been given adequate definition.

Families, regardless of the barriers, must be involved at every level. The magnitude of control the system currently has over these children and their families needs to be redirected to the families themselves, for they are the ones who best recognise and address their children's needs. Families and support providers try to manage with finite resources and often with mandate restrictions. Adequate supportive and creative provision and service co-ordination is vital if the extreme stresses commonly faced by families of children with life-threatening illnesses are to be eased.

Changes in government funding of children's services (both social and health) have made family support and assistance more accessible. A range of supports are available to enable parents to care for their children at home. The difficulty is in adapting these programs to fit the needs of this only recently recognised group. A number of government and voluntary programs do provide valuable assistance to families with a child with a life-threatening illness. Taken together, these services are a patchwork quilt of individual programs for specific needs, but there are still holes in the quilt as communities struggle to find the social supports for the ever-changing needs of this group. Arrangements for ongoing, supportive relief and funding present further challenges, as parents contend with current inadequacies and with inflexibility of supports. For these families, fragmented supports are often their only option.

When examining the philosophy and practice of supporting families who have a child with a life-threatening illness, it seems important to adopt a model that emphasises support of the family as a whole, and not just on the medical condition of the child. The practice of emergency counselling or the 'band-aid' approach (where a major crisis precipitates action) needs to be overridden. Instead, the perception of support provision for families who have a child with a life-threatening illness as having the potential to be seen as offering the chance for positive support at an earlier stage, should be favoured and encouraged.

This study has demonstrated that there are stark gaps in the way the community provides support to this specific group of struggling families. Attention has been drawn to understanding the support needs of families who have a child (or have lost a child) with a life-threatening illness. Attempts have been made to elucidate the critical issues involved in supporting families. Consequently, it is hoped that the findings of this study have highlighted the compelling need to develop a more responsive system of supports to this unique group of families who, until recent times, have been overlooked. ☐

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