

Poverty and Pediatric Palliative Care: What Can We Do?

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It has been recognized that families of children with life-limiting health conditions struggle with significant financial demands, yet may not have awareness of resources available to them. Additionally, health care providers may not be aware of the socio-economic needs of families they care for. This article describes a mixed-methods study examining the content validity and utility for health care providers of a poverty screening tool and companion resource guide for the pediatric palliative care population. The study found high relevance and validity of the tool. Significant barriers to implementing the screening tool in clinical practice

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were described by participants, including: concerns regarding time required, roles and responsibilities, and discomfort in asking about income. Implications for practice and suggestions for improving the tool are discussed. Screening and attention to the social determinants of health lie within the scope of practice of all health care providers. Social workers can play a leadership role in this work.

KEYWORDS *Child Poverty Tool and Resource Guide, content validity, life-limiting illness, pediatric palliative care, qualitative methods, social determinants of health*

INTRODUCTION

Health care providers are becoming increasingly aware of the impact of the social determinants of health on pediatric patients and their families (Bloch, Rosmovits, & Giambrone, 2011). Specifically in palliative care, health care providers are concerned with the optimal health and quality of life of patients and their families. Poverty has been found to influence health outcomes. Based on clinical experience the authors have observed that poverty can negatively impact quality of life for families receiving pediatric palliative care. Insecure housing, lack of money to pay for noncovered medications, or lack of community supports are examples of the impact of poverty on caring for children with life-limiting illnesses. In a 5-year review of the prevalence of poverty in families receiving pediatric palliative care services at a large urban Canadian pediatric hospital, Beaune and colleagues (2013) found that 62% of families who received these services lived in high poverty neighborhoods. This is likely a conservative estimate as relatively few families, who might benefit from formal pediatric palliative care services, actually access those supports (Widger et al., 2007). However, comparing this to the 12% child poverty rates in Canada (Fleury, 2008), this finding provides a strong argument that the pediatric palliative care population may be at higher risk of financial stress than the general population. A study of the financial health of families that access hospital services overall found similar elevated numbers (McNeill, 2009). McNeill's (2009) study found that families from high poverty neighborhoods have higher rates of inpatient services, increased lengths of stay, more unplanned readmissions, and experience a higher proportion of deaths compared to families from more affluent neighborhoods. Caring for a child with complex or life-limiting illness often results in reduced working hours and loss of income for caregivers, as well as an increase in medically related expenses. These can add a great deal of stress during the illness as well as a burden for the family after the death of a child. Exploring issues of poverty in pediatric palliative care has not received much attention to date and there is relatively little research in the area (Linton & Feudtner, 2008). However, it is

an important topic for further research. When a health care team is aware of family financial stressors, they can help families access resources and reduce some of the stress on their quality of life.

LITERATURE REVIEW

The World Health Organization (WHO) (2014) defines palliative care for children as “the active total care of the child’s body, mind and spirit, and also involves giving support to the family.” The definition also asserts that “health care providers must evaluate and alleviate a child’s physical, psychological, and social distress” and that it “requires a broad multidisciplinary approach that includes the family and makes use of available community resources” (WHO Definition of Palliative Care for Children section, bullets 1, 3–4).

As the philosophy of palliative care includes all dimensions of physical, psychological, social, and spiritual health of an individual and their family, it is suggested that clinicians advocate for better health care for this population, in both institutions and in the community (Liben, Papadatou, & Wolfe, 2008; McNeill, 2009). While there is an abundance of literature that focuses on the association between the social determinants of health and physical health, little is known about the particular effects of poverty on children and families receiving palliative care (Lewis, DiGiacomo, Currow, & Davidson, 2011; Linton & Feudtner, 2008). A recent Boston study in the pediatric oncology population found that 94% of families with a child who has advanced cancer had work disruptions, regardless of income level, and those with lower socioeconomic status were disproportionately impacted (Bona et al., 2013). Lewis et al. (2011) examined the association between palliative care and low socioeconomic status. They found that the distribution of services was not equitable for patients with lower socioeconomic status, particularly related to geographic access, regardless of degree of need. They also found that patients and families with lower socioeconomic status expressed experiences of stigma and mistrust in relation to health care providers, further limiting their access to services. These findings suggest that children and families with lower socioeconomic status may not be accessing much needed services (Lewis et al., 2011). This is further substantiated by data collected over a 20-year period by researchers at a UK children’s hospice, which found that children and families with lower socioeconomic status were less likely to access hospice services (Taylor et al., 2010).

Despite the fact that many families prefer their child to be at home when there are no curative treatments, a majority of children who receive palliative care die in the hospital (Liben et al., 2008). Examples of the components of a palliative care plan that would enable a family to take a dying child home are adequate nursing, medication, and medical equipment, as well as psychosocial and spiritual support. Home care services and supports suitable for the needs

of this population are not universally available in all geographic areas (Peter et al., 2007). This extends to access to pain and symptom management as well as to affordable medication (Linton & Feudtner, 2008). Families with lower socioeconomic status have been found to be less likely to access support services of all types (Moller, 2005), which is of concern in light of evidence that parents who have a child die in any setting are at higher risk of poor psychosocial and physical outcomes (Rosenberg, Baker, Syrjala, & Wolfe, 2012).

In a study by Bloch et al. (2011), it was found that doctors were unaware of adult patients' social circumstances, resulting in treatment plans that families could not follow due to an inability to afford the suggested treatments. Lewis et al. (2011) further emphasize that families referred for pediatric palliative care should have access to pain and symptom management and all of the components of good palliative care regardless of cost and where they live. Moller (2005) asserts that it is essential to move from study of this topic to activism.

Given that many children with life-limiting illness live in high poverty neighborhoods and that there is an increased financial burden to families which accompanies this care, a tool was adapted for health care professionals to raise awareness of these issues when caring for this population. The Child Poverty Tool and Resource Guide (CPTRG) represents a modification of a tool developed to address poverty in adult patients (Morinis, Levin, Bloch, & Ford-Jones, 2012). The CPTRG was further adapted to address the particular needs of the pediatric palliative care population (Beaune et al., 2013). The CPTRG consists of seven questions that clinicians can use to assess the need for financial assistance in their patient population. Included in the tool is information about federal, provincial, and regional resources related to financial support for families receiving pediatric palliative care. Later in this article we describe the reasons for a family version of the CPTRG that was developed by the authors (Appendix 1).

The aims of this study were to determine the usefulness of the CPTRG for clinicians who work in pediatric palliative care in a large Canadian city; to revise the CPTRG based on feedback from those pediatric palliative care health care providers regarding the resources and layout of the tool; to identify barriers to the usefulness of the guide; and to determine the content validity of the questions in the CPTRG.

METHODS

Procedures and Participant Selection

This study employed a mixed-methods design to explore the thoughts, feelings, and recommendations for the CPTRG by interdisciplinary health care providers that work in a pediatric palliative care setting at an urban children's hospital. The study received institutional scientific and research ethics approval.

The quantitative component utilized a content validity measure to address the validity, relevance, and feasibility of the CPTRG tool. Regular attendees of the institution's Pediatric Advanced Care Team's (palliative care) academic rounds were invited by email to join the study. Participants were asked to provide an evaluation of the CPTRG by completing a content validity measure. Grant and Davis (1997) report that assessing content validity is an important step in assessing the usefulness of a tool. The measure looks at the percentage of experts who believe individual questions and the tool as a whole to be representative of the concept being measured. This measure of content validity allows for suggestions of how to improve each question with a comments section.

The qualitative component of the study consisted of a focus group with the same health care providers. The focus group was intended to further assess and refine the CPTRG for a pediatric palliative care population. Focus groups are considered an appropriate way of collecting qualitative data and in particular for the improvement of an instrument (Linhorst, 2002). Further, Clavering and McLaughlin (2007) suggest employing focus groups when participants comprise a mix of professions in order to discern whether there are differing interpretations of the topic under discussion. The proposed number of participants in the focus group was seven or more, as suggested by Morse and Field (1995). The transcripts were analyzed using NVivo 7 software (QSR International, 2006). Conducting the focus group with a mix of professions took advantage of the combined experience in the room. The focus group was facilitated by two of the authors (LB, AL).

Data Analysis

The focus group was digitally recorded and transcribed verbatim by a member of the research team. The transcript content was analyzed by the research team using NVivo 9 (QSR International, 2010) in order to help discover themes that emerged (Barbour, 2005). Field notes were taken and analyzed by team members providing context to the interaction that occurred during the focus group (Sinuff, Cook, & Giacomini, 2012; Rothwell, 2010).

The results of the content validity test were calculated using a content validity index (CVI) or the number of items receiving a rating of 3 or 4 on a 4-point scale (Polit & Beck, 2006). The overall score for the items was expected to be above .80 or revision would be required (Grant & Davis, 1997). The intention was to use these results to better understand the attitudes and recommendations of the intended users about the CPTRG.

Trustworthiness

Scientific rigor was demonstrated by having the principal investigator and team members review the transcript separately and then discuss themes.

Verification was established by employing multiple reviewers, peer review, and member checking (Creswell, 1998).

RESULTS

Sample Description

Eight health care providers participated in the focus group ($n = 8$) including three physicians, four nurses, and one social work intern. Fifty percent of the participants reported that they had worked in health care between 6 and 10 years, 25% had 5 years or less experience, and 25% reported having 20 years or more experience. A majority (75%) of the health care providers worked in their current area of practice, pediatric palliative care, for 5 years or less.

QUANTITATIVE COMPONENT

Content Validity

The same eight respondents completed the content validity questionnaire (CVI) which is an acceptable number of experts according to Grant and Davis (1997). The tool was found to have interrater reliability calculated at .90,

TABLE 1 Interrater Reliability

Question #	Rating	1	2	3	4	Content validity
1			3	1	4	.63
2				2	6	1.00
3				2	6	1.00
4			2	2	4	.75
5				5	3	1.00
6				1	7	1.00
7			1	3	4	.88
Totals			6	16	38	
			1 or 2 = 6		3 or 4 = 54	.90

Rating scale:

1 = the item is *not representative* of financial burden.

2 = the item needs *major revisions* to be representative financial burden.

3 = the item needs *minor revisions* to be representative of financial burden.

4 = the item is *representative* of financial burden.

Questions:.

1. Do you have trouble making ends meet?

2. Do you have trouble feeding your family?

3. Do you have trouble paying for medications?

4. Do you receive the child tax benefit?

5. Do you have legal or immigration challenges?

6. Do you have a safe place to live?

7. Do you have enough help caring for your child?

TABLE 2 Content Validity Index

Question	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Expert 7	Expert 8	# in agreement	Item CVI
1	2	4	2	3	4	4	2	4	5	.63
2	4	3	4	4	4	4	3	4	8	1.00
3	4	4	4	3	4	4	3	4	8	1.00
4	3	4	4	3	4	2	2	4	6	.75
5	4	4	4	3	3	3	3	3	8	1.00
6	4	4	4	4	4	4	3	4	8	1.00
7	4	4	4	2	4	3	3	3	7	.88
Proportion Relevant:	.86	1.00	.86	.86	1.00	.86	.71	1.00	Mean I-CVI Proportion:	.89

Note. CVI = content validity index.

meaning that 90% of the responses were rated 3 or 4 in a rating scale of 1 to 4 (see Table 1). The CVI was .89 which is comfortably above the recommended standard, as the range of acceptable CVI scores in the literature is between .70 and .80 (Grant & Davis, 1997). This showed agreement from the participants that the tool was considered to be valid. Table 2 shows the data for the CVI.

QUALITATIVE COMPONENT

Thematic Findings

The content validity results clarified that pediatric palliative care providers found the CPTRG to be valid at identifying issues related to poverty within the population they provide care to. However, focus group results identified significant barriers to the use and implementation of the CPTRG by health care providers. Themes that emerged from the data are reported.

DISCOMFORT IN TALKING ABOUT MONEY WITH FAMILIES

One of the themes to emerge in the focus group was the discomfort that health care providers experience related to talking about poverty or the current financial situation of patients and families. Some examples of words and phrases that were used were: "Scared," "I don't know what to tell them," "The system isn't good enough," "Struggle," "Never as good as you want it to be," "I just don't feel comfortable," "Torn," "I'd really like it if someone would help me," "I need more information in order to ask the questions," "What if I give them this information and they ask me questions about it?" Words, phrases, and statements such as these speak to the level of discomfort that some health care providers feel when talking about a family's socioeconomic circumstances.

ROLES

There was a clear struggle for some of the health care providers in determining if identifying and addressing poverty should be part of their role. Participants stressed a number of concerns about roles that individual health care providers play. One participant (an MD) felt that addressing poverty issues was important but noted: “at the same time I do rely on working as a team and a part of me wants to say somebody else should be addressing this.” Yet, there was also recognition about the responsibility for all health care providers in addressing these issues. “I don’t think it is good enough for me to say, ‘This is somebody else’s problem on the team, not mine.’” One participant warned: “The uptake of anything new . . . is difficult in medicine.” Health care providers in the focus group agreed that they: “Would like to do more” but there are several issues holding them back. Health care providers were not sure how doing more in assessing poverty would fit into their role, but at the same time they appreciated that there are times when financial issues should be everyone’s responsibility. One example given by a participant was “[In] an urgent situation you’ve got a family who is not paying for medication, meaning they are not getting them, and their child is suffering as a result. Somebody’s got to answer to it.”

There was an assumption from some participants that social work “. . . has had additional training in how to respond” to issues such as poverty. One participant noted: “I don’t know if some of the other professions would be as comfortable with [asking questions about immigration status].” As a part of a team, the health care providers felt that their energy should be focused on the more traditional roles of the care, such as medical management for physicians. One participant thought: “I don’t think my skill set is essential for these things.” At the same time, a health care provider (nurse) felt financial issues were a part of their job. “Within my role, I’d say accessing resources is 65 to 70% of what I do. It’s huge after the child’s health and diagnosis and well-being, it’s all about this, not suggesting that we do a great job; it’s huge.”

Some participants pointed out the advantages of being able to visit families in their homes as an effective means of assessing the financial situation. “I go to people’s homes, I mean, you go to someone’s kitchen; you’re getting a lot of information pretty instantly.” Those that work in the hospital only pointed out that financial assessment is more challenging because it can be more difficult to ascertain a family’s living conditions.

SENSITIVITY IN USE OF THE CPTRG WITH THIS PARTICULAR POPULATION

The health care providers who evaluated the tool were clearly sensitive to how addressing poverty might be perceived by the families that they support. They noted that when you discuss money there may be issues of stigma, cultural influences, and privacy. “These families just have other risks.”

There was acknowledgment that while the questions were valid; they may require rewording depending on the family. One participant stated: "These are good questions but I don't ask them in a frank way." Some study participants requested that the tool be translated into other languages in order to help non-English speaking families understand the questions. In addition, there was an acknowledgment of the importance of ensuring that at risk families are not asked these questions over and over by several different health care providers as it might pose an added stress.

One of the circumstances particular to the pediatric palliative care population is accommodating the desire for the family and patient to be at home for end-of-life care. The health care providers in the study recognized the importance considering the financial requirements for a child who is receiving palliative care to be at home and the potential usefulness of the CPTRG in order to help support a family. Having an understanding of "How precarious housing might be or whether there is food on the table or what the living conditions are like" is essential in helping families make decisions about whether appropriate care can occur at home. Use of the tool can help assess a family's tangible needs with the goal of ensuring that home is a medically safe and healthy place for the child and family. Consideration of the unique needs of families is important in palliative care and therefore the use of the CPTRG may be helpful in improving quality of life for these families.

Suggestions for Use of the CPTRG

There were several themes that suggested uses for the CPTRG.

CERTAIN POPULATIONS HAVE GREATER NEED

There was acknowledgment that some families may be connected to a primary medical team well before they are referred to a specialized palliative care team, and that this team may have already connected them with appropriate financial resources. There are a few palliative-specific resources that families should be informed of when criteria are met, but for the most part participants thought the CPTRG would be more useful if it was provided to families before they were introduced to a palliative care team. Employment for parents is likely reduced if not completely on hold in order to take care of the child and needs may change when a child's care becomes palliative. One participant noted: "It is tricky and it's ambiguous. I mean everybody has taken a big financial hit with the chronically, seriously ill kid, right? This is for the families we're worried about."

Another point raised was the variation in the types of assistance available to different families. For instance, the pediatric oncology population in Ontario has financial and tangible supports that other health populations do not have access to, such as nursing support in the home and additional

funding provided by pediatric oncology interest groups. Study participants noted that for some pediatric health populations there is very little extra financial support available to families.

THE TIMING OF WHEN TO USE THE CPTRG

There were several examples described by the study participants about difficulty conceiving when to introduce the topics set out in the Tool. There are many serious discussions that take place between palliative care team members and the families they are supporting; there are competing priorities and a desire not to overwhelm families beyond where they can cope. One participant stated: “There are often a lot of things that we need to cover and you know we have consults that go from an hour to an hour and a half. So, do we now make our consults 2 hours because we are talking about these issues?” Several participants noted the challenge of finding the time to talk about financial difficulties with all the demands of their job. There seemed to be a cluster of participants that noted: “time is a challenge.” However, one participant remarked: “It probably doesn’t take up as much time as you think.”

HOW TO USE THE CPTRG

“To me the perfect solution, which I think is what this Tool is designed for, is a flag—a way of screening and bringing it to our attention because nobody is asking these questions.”

The participants recognized that the simple act of asking the questions may actually reduce the stigma experienced by some families. They noted that it is important to show: “There is a group or an individual that is open to talking about this.” There was a lot of support for the idea that the CPTRG should be used as a: “trigger,” “flag,” or a “screening” tool to ensure families have access to resources. The participants felt that the CPTRG would be an important resource especially for new practitioners. One mentioned: “I would hope this may be in my staff room or something to keep these things in mind and there are materials that can go along with it.” While the CPTRG is designed for health care providers to use, it was suggested to make a version to give directly to families, a “mandatory thing for the family to see.” This family version could be included in an information package meeting the team.

DISCUSSION

The intent of this study was to establish the usefulness of the CPTRG in identifying families struggling with issues of poverty in a pediatric palliative care setting:

We see [struggles with financial issues] over and over again with our patients and I think that having some kind of a prompt for clinicians to

be able to jump off and sort of address these things is really important.
(Focus group participant)

The original poverty tool was created to address poverty in a general adult patient population being served in clinics or a family practice (Brcic, Eberdt, & Kaczorowski, 2011). The health care providers who participated in this study were mostly hospital-based, where patients and families generally have access to social workers. There were definite assumptions by the participants that in many cases, financial resourcing is not the responsibility of all team members, such as the physicians or nurses. These findings are similar to a study by Bloch et al. (2011) which also found that some doctors did not perceive the assessment of poverty as a part of their role.

Study participants noted that some families might not routinely receive information about income and tangible resources available to them and for this reason; they saw the CPTRG as useful. Study participants struggled over whether they saw the CPTRG as something that they should or should not be responsible for, how to fit it into their busy schedules, all the while understanding the importance on families receiving this support. One participant illustrated the dichotomy in this statement:

I still struggle with how it is going to be used on the ward despite the fact that I think these things are very important. Time is a challenge and roles are a challenge and that is not to absolve myself in my personal role about what I can do.

The degree of the discomfort described in our study talking about finances was surprising in a group of health care providers that discuss difficult issues, such as death and dying, on a daily basis. The discomfort discussed by health care providers in talking about financial hardship is also seen in the literature (Bloch et al., 2011; Brcic et al., 2011). In their study, Bloch and colleagues (2011) reported that doctors did not know how to address poverty, creating a barrier to addressing the issues. In their study of the original tool, Brcic et al. (2011) asked if patients feel comfortable with their health provider asking patients questions about poverty. The response by patients was “yes” and they felt it was important to do so. It was clear in the current study that there were concerns raised by the health care providers that this was not their area of expertise and they were uncomfortable raising issues that they felt they did not have answers to. Interestingly, the authors of the study for the original tool looked to the palliative care literature as a guide for whether people felt comfortable discussing difficult topics (Brcic et al.). Palliative care is an area where health care providers are generally used to not having all the answers. Although it would seem to make sense that discussing one difficult topic should make discussing other difficult topics easier, this did not appear to be the case in this study. We did not look at the reasons for this discomfort in talking about finances and can only speculate about the underlying cause.

Perhaps, as some of the health care providers suggested, they do not actually see the impacts of poverty when patients are in the hospital as they would if they visited patients at home.

A range of opinions were expressed on whether discussing finances should be a part of the role of all members of an interdisciplinary team in a palliative care setting or mostly the role of the social worker. It may be important to keep in mind that many palliative care teams may not have direct access to a social worker or may not have an automatic referral process.

Other pediatric practitioners are beginning to note the importance of screening for the impact of the social determinants of health in their practice because of their impact on the whole family. However, there are challenges getting health care providers to change their approach by including assessment of financial hardship as part of their standard practice (Kenyon, Sandal, Silverstein, Shakir, & Zuckerman, 2007, Garg & Dworkin, 2011). Garg and Dworkin (2011) noted that there are many competing priorities for pediatric practitioners who may perceive adding an additional one as daunting.

The participants in this study felt that families are usually overwhelmed with the sensitive and emotional content of the conversations they have on first meeting with the palliative care team. They believe that families need some time to digest this information and thus it may be appropriate to discuss finances at a later time. Quite a bit of the discussion concerned how the questions were asked, whether they were appropriate for this particular audience and whether there should be other considerations. In considering which families this revised Tool could help, health care staff should be reminded that 62% of the families referred to the palliative team live in high poverty neighborhoods (Beaune et al., 2013).

Previous work has shown the original tool to be both sensitive and specific identifying adult patients in a family practice in need of assistance with issues related to poverty (Brcic et al., 2011). Our quantitative findings demonstrate that a multidisciplinary group of experts practicing in the field of pediatric palliative care believe the CPTRG to be a useful tool for identifying issues of poverty that may impact the children and families they care for. The analysis of the transcripts from the focus group and the results of the content validity test resulted in information that was subsequently used to guide further adaptation of the CPTRG.

Based on the study findings, the authors have completed a draft of a family version of the CPTRG which can be updated with local resources suited to any setting and translatable into other languages as appropriate. The tool gives the families time to reflect on their financial and tangible needs (see Appendix 1). It will be important to ensure that the tool for families does not substitute for the important discussion between families and health care providers. One participant reinforced this concern: "I have a fear that maybe it's one of those things that . . . if you don't come out and ask the question it sort of just gets slid under the carpet."

Limitations

There are several limitations to this study. The focus group that participated in the study may not be representative of all pediatric palliative care professionals. As the settings where pediatric palliative care takes place are varied, these results may not reflect attitudes in other hospitals, in outpatient settings, or in other communities where pediatric palliative care is provided. Another limitation is that the focus group comprised only some of the health care professions who participate in the delivery of pediatric palliative care. There may have been thoughts, views, and attitudes that were missed as a result.

IMPLICATIONS FOR PRACTICE AND FUTURE DIRECTIONS

Issues of poverty are important topics to be addressed by health care professionals directly with families as well as through advocacy efforts to change practice and policy at governmental and hospital levels. Even in a comparatively well-resourced area such as Ontario, disparities in health care still exist (Bloch et al., 2011). The goal of using the CPTRG is to increase awareness of financial issues facing families and improving access to resources that are already available. While social workers in interprofessional teams are well placed to advocate for clients with limited financial resources, they can also encourage the use of evidenced-based tools, such as the CPTRG, by all health care providers. Advocating for hospital wide use of such tools can ensure that those teams without social workers provide excellent care to families struggling with financial issues. Having the CPTRG available together with a family companion guide may encourage health care providers to approach this difficult and uncomfortable topic with a little more confidence, ensuring that assessing and addressing poverty in pediatric palliative care is considered the responsibility of all.

This was a preliminary study exploring the usefulness of the CPTRG in a pediatric palliative care health care setting. The tool and its draft family companion guide were developed such that they could be easily adapted for any setting or pediatric population. Our study suggests key areas for further research on the impact of the social determinants of health in pediatrics as well as offering two clinical tools (a child poverty screening tool and the family companion resource guide) for all health care providers for use in their own practice. Reporting of the use of the CPTRG in other settings would give a better indication of the usefulness of this tool in pediatric palliative care more generally. It could also be useful to more deeply explore the reasons for the discomfort of health care professionals in discussing finances in order to address this barrier to use of the CPTRG, as well as to practice in general. Lastly, it would be helpful to assess the usefulness of the family companion guide from the perspective of families.

CONCLUSION

The quantitative component of this study found that the CPTRG is a valid tool for identifying issues of poverty in families with a child receiving palliative care and a useful resource for practitioners. The qualitative component illuminated the barriers to use of the CPTRG—including the time involved in discussing finances, whose role it is to bring up this discussion, and discomfort in talking about finances. Participants in this study strongly recommended a companion tool that would provide families with financial resources which has been subsequently developed by the research team (Appendix 1). This family companion guide was recommended to provide direct information to families, to reduce time and discomfort on the part of the health care professionals, and as a preparation for families to have subsequent discussions with their palliative care team.

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APPENDIX

Resources, Continued

6. Safe place to live - continued

Toronto Community Housing Corporation -Affordable housing help • 416-981-5500
<http://www.torontohousing.ca/>

Housing Connections, Toronto
 Special Priority Housing • 416-981-6111

7. Do you have enough help caring for your child at home?

Compassionate Care Benefit
 Employment Insurance Benefit
 1-800-206-7218 (TTY: 1-800-529-3742)

Employment Insurance Benefit for
 Parents of Critically Ill Children
 (expected to be available June 2013)

Community Care Access Centres (CCAC)
 Home nursing visits, care coordinator, social workers,
 physiotherapists, personal support workers www.ccac.on.ca • 310-CCAC (310-2222)

Special Services at Home (SSAH)
 Ministry of Community and Social Services
 Toronto Regional Office
 416 325 0500

ACSD Assistance for Children with Severe Disabilities -
 includes respite care
<http://www.respiteservices.com/Toronto>
 416 322 6317 ext.1 (416 322 7877 ext. 280)

Hospice Toronto – Volunteer Hospice Palliative Care
 support
www.hospicetoronto.ca • 416-364-1666

Tammy Latner Center for Palliative Care
 Visiting palliative care physicians to families in the
 City of Toronto
www.tlcpc.org • 416-586-4800 ext. 7884

Bereavement and Grief Support

The Unforgettables Fund
 Funds that support funerals and burials

Children's Wish Foundation – Provide children
 living with high-risk, life threatening illnesses with
 the opportunity to fulfill a wish
 905-831-9474 • 1-800-267-9474
www.childrenswish.ca

*This brochure is adapted from original work by
 Health Providers Against Poverty
www.healthprovidersagainstopoverty.ca*

THE HOSPITAL FOR SICK
 CHILDREN
 555 UNIVERSITY AVENUE
 TORONTO, ONTARIO
 M5G 1X8

FAMILY
FINANCIAL
SUPPORT

*A Resource Guide for
 Children with Complex
 Medical Conditions*

Parents of children with complex medical conditions have told us they struggle with finances.

There are resources in this guide that may help with some of the challenges. You may find that only some of the resources apply to you. If you are having a hard time figuring out how to apply for these supports, please ask.

Experiences of Parents

Families tell us that caring for a very ill child can mean extra financial stress. Families often tell us:

- They have trouble making ends meet.
- They sometimes have trouble feeding their family.
- They have trouble paying for medications.
- Are not aware of benefits they are eligible for.
- They have legal or immigration challenges.
- They do not have a safe place to live.
- They do not have enough help caring for their child or children.

What can be done?

- Provincial and Federal benefits
- Do your taxes
- Explore other programs
- Please read on to find out about resources in the area.

*"Families tell us that caring
 for a very ill child can mean
 extra financial stress. "*

Resources**1. Do you have trouble making ends meet?**

The Provincial and Federal Government offer benefit programs that can help:
www.canadabenefits.gc.ca
www.ontario.ca/BenefitsDirectory
 Ontario Disability Support Program
[www.mcsc.gov.on.ca/en/mcss/programs/social/odsp/Ontario Works](http://www.mcsc.gov.on.ca/en/mcss/programs/social/odsp/Ontario%20Works)
www.mcsc.gov.on.ca/en/mcss/programs/social/ow
 Getting help doing your taxes can save you money and help you access programs and benefits:
 Community Income Tax Clinics
 1-800-959-8281 •

2. Do you have trouble feeding your family?

Daily Food Bank
 416-203-0050 • www.dailybread.ca
 School aged children www.breakfastclubscanada.org
 FoodLink HotLine – food program listing
 416-392-6655 • www.foodshare.net

3. Do you have trouble paying for medications?

Ontario Drug Benefit Program
 Financial assistance for households that spend a large portion of its income on prescribed drugs
 416-314-5518 • 1-800-268-1154
www.drugcoverage.ca

4. Do you receive the child tax benefit?

Canada Child Tax Benefit • Help with costs of raising children •
 Universal child care benefit and children's special allowances • Child Care Support
 1-800-387-1193

Ontario Trillium Benefit • 1-866 668-8297

5. Do you have legal or immigrations challenges?

Multicultural Health and Community Services
 416-324-8677 www.accessalliance.ca
 Community Legal Education Ontario (CLEO)
 Legal Help. www.cleo.on.ca

Legal Aid Ontario – Legal help
 416-979-1446 • 1-800-668-8258
www.legalaid.on.ca

OCASI-Settlement – Immigration help
 416-322-4950 • www.settlement.org

6. Do you have a safe place to live?

Assaulted Women's helpline
 416-863-0511
 Domestic violence against women
 416-323-9140 • www.schliflerclinic.com
 Toronto Homeless Services
www.toronto.ca/housing
 Emergency Shelters 1-877-338-3398
www.toronto.ca/housing