

Measuring the Quality of Children's End-of-life Care

Summary of Research Project

A child's death has a widespread and long-lasting impact on parents, siblings, extended family, the community and those who care for the child. Therefore it is important that the care be of the highest quality.

In this research we are developing and testing a survey which asks bereaved parents to report on various aspects of care provided to their child and family before, at the time of, and following the death of their child. Through a review of existing research with parents we have identified care needed in five areas by parents from health professionals in order to have high quality care. The areas are: connect with families, involve parents, alleviate suffering, share information, and provide bereavement care. The research has three phases. In Phase 1 will have focus groups with parents. I will ask parents what they believe is important to quality end-of-life care for children and their families. Phase 2 will involve creating the survey questions about quality care. The questions will be based on what parents said was important during the focus groups. When all the questions are created, we will ask health professionals and parents to review the questions to make sure they are clear and easy to understand. We will also ask if the questions seem to be about quality care and if anything is missing. Between 5 and 10 parents will take part in Phase 2 of the study. Phase 3 of the study will involve about 100 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children's end-of-life care. Part of the study will also look at the best way to ask parents about the care they received and to make sure that these type of questions do not cause a burden to parents.

The survey developed in this study will provide a way for health professionals, health systems, and policy makers to improve care provided to families facing the death of a child. My hope is that once the survey is developed and is shown to work well to measure the quality of care, it will be used in hospitals across Canada to give bereaved parents the chance to give feedback about all of the good and not so good things they experienced so health professionals are always listening to parents and working to give the highest quality care to families.

Measuring the Quality of Children's End-of-life Care Consent Form for Phase 1 Focus Groups



Principal Investigator

Kimberley Widger RN MN
PhD Candidate
Faculty of Nursing
University of Toronto
130 - 155 College Street
Toronto, Ontario M5T 1P8
Phone: 416-978-2859
Fax: 416-978-8222
kim.widger@utoronto.ca

Dr. Ann Tourangeau RN PhD
PhD Candidate Supervisor
Assistant Professor
Faculty of Nursing
University of Toronto
130 - 155 College Street
Toronto, Ontario M5T 1P8
Phone: 416-978-6919
Fax: 416-978-8222
ann.tourangeau@utoronto.ca

Funding: The Innovation Fund in
Children's Palliative Care
Research

What is the purpose of this research?

We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we will have focus groups with parents. We will ask parents what they believe is important to quality end-of-life care for children and their families. We will have between 3 and 5 focus groups with 6 to 8 parents in each group. All groups will be held in the Toronto or Hamilton area. The second phase will involve creating the survey questions about quality care. The questions will be based on what parents said was important during the focus groups. When all the questions are created, we will ask health professionals and parents to review the questions to make sure they are clear and easy to understand. We will also ask if the questions seem to be about quality care and if anything is missing. Between 5 and 10 parents will take part in phase two of the study. The third phase of the study will involve about 100 parents. These parents will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children's end-of-life care.

We invite you to take part in the first phase of our research. If you want to take part in the other phases of the research you can tell us this at the end of this consent form. If you only want to take part in this first phase of the research, that is fine too.

Who can take part in this study?

To take part in this study you must have experienced the death of a child at least 1 year ago. You must be the biological, step, or adoptive parent of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital after being admitted for at least 24 hours or died within 24 hours due to a life-threatening illness or at home due to a life-threatening illness. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?

We will hold the focus groups in the Toronto or Hamilton area in a private room. We expect each focus group to last about 2 hours. There will be 6 to 8 parents in each group. The groups will be led by the main investigator and a research assistant. In the focus group, we will ask what you think health professionals should do to give the highest quality care to children and their families. All of the discussion will be audiotape recorded and then written out on paper. We do this so we can review what was said after the group and make sure we did not miss anything.

What are the risks of taking part in this study?

It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop taking part in the focus group at any time. If you decide to stop, anything you have said during the group up to that time will still be included in our analysis. If you become upset the investigator can spend time talking with you. The investigator can also refer you to someone else to help you if you wish.

What are the benefits of taking part in this study?

There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child's death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?

Confidentiality can only be guaranteed to the extent permitted by law. Confidentiality can only be maintained if parents who take part in the group do not talk about what went on in the group with other people. The audiotapes will be erased after the discussion has been written out on paper. Your name and other identifying information will be removed and kept separate from the data. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?

The results from this phase of the study will be used in the next phases. If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child's name would not be included in these quotes. You can ask to have a copy of the results sent to you at the end of this consent form. Updates about the study and results will be posted on the following website:

<http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm>

There are also links on this page to other websites that you may find helpful in coping with your child's death.

The survey questions that will be made using the results from this study will be free for use by any health professional who wishes to use it. The investigator will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?

At the end of the focus group you will receive \$40 to thank you for sharing your experiences with us. If you come to the group but decide to withdraw from the study part way through the group, you will still get the full amount. If you agree to attend the group but then do not come to the group, you will not get the money. We will provide drinks and snacks during the focus group session.

Who do I contact if I have questions?

If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca

If you have questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

How do I get a copy of the results of the study?

You may ask for a copy of the final reports from this study.

I would like to receive a copy of the final report for the first phase of this study.

I would like to receive a copy of the final report for the whole study.

If so, please provide an email address or a mailing address where you would like the results sent.

How do I take part in the next phases of the study?

I am willing to be contacted by the investigators to take part in the second and/or third phase of the study. Contact telephone number: _____

CONSENT

I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. I consent to having the focus group discussion tape recorded. A copy of this form has been given to me. I voluntarily consent to take part in this study.

Participant Name (Print)

Participant Signature

Date

Name of Person Witnessing Consent
(Print)

Witness Signature

Date

Focus Group Questions

1. What does quality end-of-life care mean to you?
2. What are the most important things health professionals should do to provide high quality end-of-life care to children and their families?
3. How important is it for bereaved parents to be asked for feedback about the care they and their family received?
4. What is the best way to approach parents and ask them for their feedback? For example do you think the telephone, written questions, in-person interviews or questions on the web would be the best?
5. When is the best time to ask? Should these questions be asked in the first few weeks? After 6 months? After a year? Longer?
6. One concern with doing this type of research with bereaved parents is that it will be emotionally difficult for them to talk about their child and the experiences around their death. What do you think about this concern?
(Specific impact questions are attached) Do you have any concerns for how these questions are worded?
7. When we ask parents about the care that they received we will also need to ask a few questions about the child and how and where they died. We will also need to ask some questions about the parent who is answering the questions. (Questions on background and demographics are attached) Do you have any concerns for how these questions are worded?

Questions on Impact of Participation

1. How valuable is it to conduct research about parent's views on the quality of care given by health professionals?

Not valuable

A little valuable

Very valuable

2. Why did you agree to participate in this research study? (Check all that apply)

- To help others in a similar situation
- So I could talk about the experience I had
- Was pressured by my family/friend
- Was pressured by the researcher
- Other (please explain) _____

3. How painful was it to participate in this study?

Very painful

A little painful

Not painful at all

4. Compared to what you might have been expecting, were the questions:

More painful than expected

About what I expected

Less painful than expected

5. Overall would you say participating in this study had a positive or a negative effect on you?

Very positive

A little positive

Neither positive or negative

A little negative

Very negative

6. Do you regret participating in this study?

Yes

No

7. Would you recommend to another bereaved parent that they participate in a similar study?

Yes

No

8. Which do you think would be the best way to ask parents the survey questions? (check one)

- A researcher asking the parent questions over the phone
- A written survey the parent fills out by themselves
- A researcher asking the parent questions in person
- A survey that the parent fills out on a website
- Other (please explain) _____

9. Please share any other comments about how participating in this study has affected you.

Questions for Background and Demographic Information

Background

1. What was the name of your child who died? _____
2. Was your child a boy or a girl?
 - Boy
 - Girl
3. What was the date of his/her birth? _____ dd/mm/yy
4. What was the date he/she died? _____ dd/mm/yy
5. What was the cause of death? (if known) _____
6. What was his/her diagnosis? (if applicable) _____
7. Where did he/she die?
 - Hospital name _____ (indicate community hospital or tertiary centre)
 - ICU/NICN
 - ER
 - another unit
 - other _____
8. How long was he/she in hospital during that last stay before he/she died? _____ days
9. Approximately how long before _____'s death did you know that he/she was likely to die?
 - 6 months or more
 - 1 month to 6 months
 - Days to 1 month
 - Less than 7 days
 - 1 day or less
 - I didn't know until it happened
10. Was there a palliative, hospice, or supportive care team or service involved in your child's care?
 - Yes
 - No
 - Don't Know
11. Was there a bereavement service connected with the hospital that provided care to you after your child died?
 - Yes
 - No
 - Don't Know
12. Including your child who died, how many children do you have? _____

Demographics

1. What is your relationship to the child who died?

- Biological mother
- Biological father
- Adoptive mother
- Adoptive father
- Step mother
- Step father

2. What year were you born in? _____

3. What is your current marital status?

- Married or living as married
- Divorced or separated and not presently remarried
- Never married
- Widowed
- Other (please specify): _____

4. What is the highest level of schooling you have completed?

- Elementary school or less
- Some high school
- High school diploma
- Some college (including CEGEP) or trade school (but did not complete a diploma)
- Diploma from college or trade school
- Attended university (but did not complete a degree)
- University degree
- Post-graduate degree
- Other (please specify): _____

5. What is your total family income?

- under \$20,000
- \$20,000 – \$39,999
- \$40,000 - \$60,000
- above \$60,000

6. Which ethnic or cultural groups do you (or the majority of your ancestors) belong? List more than one if necessary.

7. Which religion do you belong to (if any)? _____