Being a Family in the Midst of Living and Dying

SUSANNE M. SYRÉN, BRITT-INGER SAVEMAN, and EVA G. BENZEIN, Department of Health and Behavioural Sciences, Kalmar University, Kalmar, Sweden

Abstract / The aim of this study was to illuminate the way of being a family when one family member is in the midst of living and dying. A family systems frame and a life world perspective were used in interviews with five families. A qualitative analysis inspired by Giorgi revealed dialectic and dynamic processes in constant motion within and between the continua being in affinity-being in loneliness, being in power-being in helplessness, and being in continuity-being in disruption. When families were moving in the direction of being in affinity, power, and continuity, these seemed to be prerequisites for enduring their challenging life situation and for giving them a kind of reposé. When the movements were in the opposite direction, existential and emotional suffering were manifested as individual embodied experiences such as depression and anxiety.

Résumé / Cette étude avait pour objectif de mettre en lumière la façon d’être d’une famille alors qu’un de ses membres est sur le point de la mort. Nous nous sommes basés sur le cadre de structure familiale et sur une perspective axée sur le milieu de vie des familles pour conduire les interviews. Une analyse qualitative inspirée par Giorgi nous a révélé qu’il existe des processus dialectiques et dynamiques en constante évolution à l’intérieur de chacun des pôles et entre l’ensemble des pôles formant le continuum. Ces pôles sont : être en affinité—être isolé ; être en contrôle—être impuissant ; être conséquent—être bouleversé. Lorsque les membres des familles démontrent dans leur comportement qu’ils étaient en affinité, en contrôle et conséquents, ces pôles semblaient être les préalables nécessaires pour les aider à faire face à ce grand défi de la vie et leur donner une certaine quiétude. Par contre lorsque c’était le contraire, les souffrances existentielles et émotionnelles étaient plus marquées alors que certains membres des familles souffraient d’anxiété et de dépression.

INTRODUCTION

"Receiving a diagnosis of cancer is described as being pushed out of a helicopter into a jungle war without any training, any familiarity with the terrain, or any sense of how to survive" (1). The onset of such a serious disease forcefully challenges emotional and physical boundaries in families. The disease is an uninvited guest that must be incorporated into families’ lives (2). When cancer becomes incurable, families have to face the obvious physical deterioration of a loved family member and also the reality of death. In some families, the energy required for keeping thoughts of illness and death away may have a negative effect on interactions and communications between family members. In other families, the situation can involve meaningful conversations, time for retrospection, summary of life, and time for conflict resolution and farewell takings (3). Family members’ various meanings ought to be considered when trying to understand families’ experiences of their life situation. In order to understand relationships between family members, the focus ought to go beyond the limit of the individuals (4) and view family as a relational ontology, that is, as a way of being (5,6).

Despite the call for nursing research involving the family as the unit for data collection, that is, when the ill person and other family member/s are present simultaneously, such studies are rare (7). One reason may be methodological problems (8,9). A literature review showed that family research until now has had low priority among oncology nursing researchers (10). As far as we can identify from a systematic literature review in the databases Cinahl, Medline, and PsychInfo, only one such study was found, in which one family member is living with cancer in a palliative stage (11). However, a great number of studies in which the family is represented by one voice are quite well studied in the palliative context, but will not be presented here. Reimer et al. (11) illuminate families’ experiences and life situation when one family member is “fading away”, and the transition between living with cancer and dying of cancer. Families move into disorganization between the past, the present, and a new confusing reality. The ongoing process demands that families continuously reassess their life situation and their roles. Consequently, there is a need for more knowledge, from a relational family unit perspective, of families in the palliative phase of a cancer disease. This study focuses, therefore, on aspects of the relational life world of families (5–6), which emphasizes circular causality and acknowledges that a change in one part
of the family will inevitably bring a change in the other parts.

**Aim**

The aim of this study was to illuminate families' way of being in the midst of living and dying, when one family member is diagnosed with cancer in a palliative phase.

**METHODS**

**Participants and Setting**

The inclusion criteria for the study were families with one family member diagnosed with cancer in a palliative phase, cared for at home, speaking Swedish, and being aware of the disease prognosis. Each ill family member, together with their close family member/s, was asked to decide what persons should represent their family at the interviews (12). Five families connected to one hospital-based palliative care team agreed to participate. Two families declined participation; one ill family member felt too unwell to participate and, in the other family, all but the ill person declined participation. For one family which had agreed to participate, the interview could not be carried out as the ill person died before it could take place. Genograms and family characteristics for participant families are presented in Figure 1.

**Procedure**

Nurses in the hospital-based palliative care team gave short verbal and written information about the study to families that met the study's inclusion criteria. After permission was received from the ill family member, the researchers phoned them and gave further information. All participants were informed verbally and in writing of their right to withdraw their participation whenever they wanted to. Confidentiality was

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**Figure 1 / GENOGRAMS AND FAMILY CHARACTERISTICS**

<table>
<thead>
<tr>
<th>Family 1</th>
<th>Family 2</th>
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<tbody>
<tr>
<td><img src="image1.png" alt="Genogram" /></td>
<td><img src="image2.png" alt="Genogram" /></td>
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<table>
<thead>
<tr>
<th>Family 3</th>
<th>Family 4</th>
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<tbody>
<tr>
<td><img src="image3.png" alt="Genogram" /></td>
<td><img src="image4.png" alt="Genogram" /></td>
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</table>

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<thead>
<tr>
<th>Family 5</th>
<th>Symbols</th>
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<tbody>
<tr>
<td><img src="image5.png" alt="Genogram" /></td>
<td><img src="image6.png" alt="Symbols" /></td>
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</tbody>
</table>

**Participating in interviews:**
- Family 1 - John (ca prostate, palliative phase for 10 months), wife Lill
- Family 2 - Joan (ca mammae, palliative phase for 22 months), husband Jeff
- Family 3 - Judith (ca mammae, palliative phase for 35 months), partner Carl
- Family 4 - Ann (ca ventriculus, palliative phase for 7 months), daughter Carol
- Family 5 - Margreth (ca pancreas, palliative phase for 17 months), husband Ronald

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guaranteed. The study was approved by the research ethics committee at the Health University in Linköping, Sweden (Dnr. 01-225).

**Interviews**

Narrative (13) family interviews were conducted in the families' homes with two researchers present. The interviews were conducted in such a way that the family members and the researcher jointly constructed the meaning of questions and answers through dialogue. One researcher conducted the interview, and one acted as an observer and simultaneously completed field notes. The aim was to reveal the families' thoughts, experiences, and behaviours in relation to the illness. In the beginning of the interviews, each family member was asked to narrate his or her illness story, and a genogram was drawn in order to visualize the family structure and to initiate relational thinking (12). The follow-up questions were related to the content of the family members' stories and also as a means of ensuring the meaning of their stories was correctly understood by the researchers. In order to reveal the families' own understanding and illness beliefs, and to stimulate reflections on relationships in the family, circular questions were used (14,15). Examples of circular questions on the cognitive, affective, and behavioural domains of family functioning (12) used in the interviews are shown in Table 1. The tape-recorded interviews lasted for about 90 minutes and were transcribed verbatim.

**Analysis**

A qualitative analysis inspired by Giorgi (16,17) was used. First, the text was read through to obtain a preliminary understanding of the life world of the families. Second, meaning units—parts in the text related to their content—were identified. Third, the meaning units were transformed from verbal to written language, that is, they were expressed in a more abstract way. Fourth, these abstractions were compiled into groups of intersubjective subcategories. Fifth, six categories emerged which, in pairs, were in a dialectic and dynamic relation to each other. Lastly, a synthesis of the categories with an intrasubjective focus was proposed. The primary analysis was performed by the first author. The second and third authors followed the analysis process, and consensus was reached on the final interpretation. Examples from the analyses are shown in Table 2.

**FINDINGS**

Being a family when one family member is living with cancer in the palliative phase involves dialectic and dynamic processes in constant

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**Table 1 / EXAMPLES OF CIRCULAR QUESTIONS USED IN THE INTERVIEW**

<table>
<thead>
<tr>
<th><strong>Cognitive Domain</strong></th>
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<tbody>
<tr>
<td>What do you know about your husband's disease?</td>
<td></td>
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<tr>
<td>What information has been most useful?</td>
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<table>
<thead>
<tr>
<th><strong>Affective Domain</strong></th>
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<tbody>
<tr>
<td>In what way do you share your wife's feelings?</td>
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<tr>
<td>How do you think this is affecting your daughter?</td>
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<tr>
<td>Who in your family worries the most?</td>
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<table>
<thead>
<tr>
<th><strong>Behavioural Domain</strong></th>
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<tbody>
<tr>
<td>What is the biggest change in your daily life since X got sick?</td>
<td></td>
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<tr>
<td>If X gets worse, what will you do?</td>
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</tbody>
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**Table 2 / EXAMPLES FROM THE ANALYSIS**

<table>
<thead>
<tr>
<th><strong>Meaning Units</strong></th>
<th><strong>Abstractions</strong></th>
<th><strong>Subcategories</strong></th>
<th><strong>Categories</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>A4: We have been open with each other, talking about everything and not hiding anything.</td>
<td>The mother believes that the family members are open to each other.</td>
<td>Openness</td>
<td>Being in affinity</td>
</tr>
<tr>
<td>B4: ...It's probably harder for those who weren't so open before. Obviously it's a huge shock to get cancer, but I mean, it was quicker for us to come to terms with it...now we're struggling on...but a lot of people who don't have anybody to talk to can get very low at once and then don't come up again.</td>
<td>The daughter believes that openness has helped them to come to terms with the situation.</td>
<td>Openness</td>
<td>Being in affinity</td>
</tr>
<tr>
<td>A1: Yes, and then people react so differently too, don't they?...and some don't want to talk about it at all, and others you can talk to, and a third category you mustn't talk to. You have to be damned careful about that.</td>
<td>The man says that some people's reactions show that they are not suitable to talk to.</td>
<td>Insecurity</td>
<td>Being in loneliness</td>
</tr>
<tr>
<td>B1: (sigh) I don't know. I don't talk so much with other people anyway...I think you're more open. A1: Yes, I admit I have talked too much. B1: Yes, I think you have.</td>
<td>The woman does not talk so much with other people but the man believes that he has talked too much, and the woman agrees.</td>
<td>Withdrawal</td>
<td></td>
</tr>
</tbody>
</table>
motion between and within the poles of the continua: being in affinity—being in loneliness, being in power—being in helplessness, being in continuity—being in disruption.

In the following report, A indicates quotes from ill family members, while B indicates quotes from other family members.

**Being in Affinity—Being in Loneliness**

This continuum involves one pole named "being in affinity", characterized by openness and comfort, and one pole named "being in loneliness", characterized by insecurity and withdrawal. In order to be in affinity, it seems necessary to be together in the family to endure the present life situation. Sharing thoughts and feelings generates inner strength and the courage to be even more open. Families who had open communication before the onset of the disease seemed to keep that pattern throughout the illness. Reciprocity in families also created experiences of comfort, which was related to their will to be available for each other and to protect each other from individual suffering. Even small children expressed their interest in giving comfort.

B4: We were here visiting. My smallest boy who was three years old was with us. I had told him that grandma was sick and he asked if you were going to die.

A4: Yes, I answered that I probably wouldn’t. When you came for me in the car, he thought I was so poorly that I needed to lie down in the back seat.

B4: Yes, and he asked if you needed a sticking plaster since you were sick.

Within the transition from being in affinity towards being in loneliness, insecurity stands out as a prominent feature. Insecurity was related to the fear of exposing each other to suffering their own anxiety and, therefore, withdrawal from conversations in the family. Another aspect of insecurity was related to experiences of not having enough knowledge of the disease and uncertainty about what to ask health care staff. Sometimes they were unsure if they had the right to disturb the staff, despite their needs. Insecurity was also related to the reactions of other people, and to the families’ expectations of how others would react to changes due to the disease.

A1: People react so differently. Some don’t want to talk about it, others you can talk to...but there’s a third category you shouldn’t talk to, that’s when you have to really watch out.

B1: Yeah I know...I don’t talk so much to others in any case.

A1: Well I admit I talk too much.

B1: Yeah, you’ve done that.

**Being in Power—Being in Helplessness**

The continuum from being in power to being in helplessness involves the transition from the ability to manage the life situation to a lack of resources both inside and outside the family. Being in power is nurtured and deepened by the experience of having lived through earlier life difficulties, but also by a readiness to manage the life situation using available resources. This was shown when families described how they live a “normal” life.

B5: This week I’ve been able to cycle to work, I’ve longed for that. The weather has been okay and you haven’t had anything at the hospital.

A5: It’s the little things that give you pleasure sometimes, when I don’t have any pain, when I think everything is working all right...

Being in power was also characterized by an ability to use necessary strengths and the presence of flexibility in daily life. This included the importance of learning how to adapt to the new life situation. Families spoke of avoiding thinking and talking too much about the disease or the possibility of a long survival. Family members’ inner strength could emerge from negative feelings, such as anger, but also through the use of humour. For example, when watching funny movies, the illness experience could be transcended and forgotten for a while. A supply of flexibility was emphasized, for example, by being able to change domicile, to change responsibility and work tasks, and to change routines for maintaining social relations. This flexibility also included the availability of health care such as, for example, being assured of a place in hospital whenever needed.

B2: It was a trying time then, but we managed.

A2: And that makes you strong—you do it together.

B2: It makes you strong.

A2: I think I can say that I’m a fairly strong person by nature, largely thanks to [the therapist] of course.

B2: ...and I’m a very rational person. We have managed it once, we’ll manage it again. Besides, I have a good boss who makes it possible for me to be flexible at work.

Being in helplessness was characterized by lack of sufficient resources to understand and manage the situation in relation to the disease. The families told of their helplessness when they did not know how to act in various situations. They sometimes felt out of control, when all energy was needed for thoughts about the disease, when they had no faith in relationships with health care staff, when they evaluated the care as not helpful, and
when there was an imbalance between demands and expectations.

A2: I tried to support you but you just said no, no, no...

B2: It was too much, all the practical things...and all that taking care of the bother. Dad was disabled, you were at your worst, what would happen to our daughter?...all the thoughts that came into my head.

Being in Continuity—Being in Disruption

This continuum involves the poles of being in continuity and being in disruption, and focuses on life, mortality, and death. The formulations of these issues and the reflections they arouse in families may lead in two directions: toward awareness and reconciliation of the life situation, or toward a stance where failings and losses seem overwhelming and are difficult to assimilate. Even when families were resigned to the situation, life and death were hard to communicate.

B3: The worst thing right now is, if [ill family member] should die, it's really difficult to think of that.
A3: I will die, I promise you, I will.
B3: Yeah, so will I.
A3: That's the only thing that's certain...you can't get away from that.

Being in continuity seems to be prominent in families as they express awareness of the loss death can mean. In spite of this, they are able to live in acceptance of the present and manage to face the uncertainty of the life situation. Being in continuity also involves experiences of significant relationships in the past, the present, and in a distant future. The experience of continuity is embedded in family members' will to go on living and to keep up traditions after the death of the dying family member.

A1: We've been out a lot...it would be nice to see our house in the archipelago one more time.
B1: That's something we've done for many years, hunting and fishing...that has been everything (laughter). But both the boys have taken up that interest, so I suppose they'll carry on.

The experience of being in continuity arises in intimacy with dead loved ones. The families told about how experiences of contacts with dead relatives and the memories of them gave confidence about the eternal life of our souls. The families also told about their experience of a spiritual power or a Christian faith as sources of trust and confidence.

B2: I had strong feelings together with them, that still helps me. Sometimes I still talk with my dead father.

A2: I think he's still here in some way, it's the same with my brother. He slept the whole last week he was alive, but we had contact in any case.

Being in disruption is characterized by uncertainty and termination. When the awareness of mortality became obvious, the future was experienced as dramatically limited and plans were made for just the immediate future. The families told how they did not dare plan for a distant future, but only set up short-term goals. The awareness of dying and death may be so hard to bear and to think of that families are not able to find peace in the present at all. Death was expressed as disgusting and as a termination which is almost impossible to consider.

A1: I don't see any future at all, just an end.
B1: I don't think at all. The days just pass.

Synthesis

The dialectic and dynamic processes between and within the continua seem to be in constant motion and have decisive importance for the families' way of being. When these movements are in the direction of being in affinity, in power, and in continuity, this seems to enable families to endure their challenged life situation together, giving them a kind of repose. In contrast, when the movements are in the direction of being in loneliness, in helplessness, and in disruption, the unbearable becomes a reality for the individuals in the family. Then, the existential and emotional aspects of suffering seem to escalate, and are manifested as individual embodied experiences, such as depression and anxiety.

DISCUSSION

The most important findings in this study are the dialectic and dynamic movements between and within the continua being in affinity—being in loneliness, being in power—being in helplessness, and being in continuity—being in disruption, which reflect families' ways of being in the midst of living and dying when one family member is diagnosed with cancer in the palliative phase. Living in such a life situation is characterized by fluctuating experiences over time and a life in constant motion. The stories of the individuals in the families and the interactions and interplay between them revealed the families' way of being. The background processes can be supported by ideas of hermeneutics, where the understanding of life can be found as never-ending spiral movements from the parts to the whole and back again (18). The movements within the continua relate to the interactional dynamics inside and outside
families, and can be understood in a systems theory framework (12). Within this framework, individuals' lives are always lived in a changing dynamic with others. In the dynamic of family life, there are more than the lives of the individuals separately and more than the summarized interactions between family members.

To understand the complexity of the movements between the three continua, it can be helpful to illuminate the different ways of being a family by using Eriksson's (19) ontological health model. In this model, health is equivalent to living in balance and harmony in the dimensions of doing, being, and becoming. In the present study, the continuum being in power-being in helplessness can be compared to the dimension of doing, that is, the ability to understand and act in relation to the illness. The continuum of being in affinity-being in loneliness, can be compared to the dimension of being, focusing on the relationships with the surrounding milieu and other people. Finally, the continuum being in continuum-being in disruption can be compared to the dimension of becoming, in which human beings have contact with and reflect upon existential issues of life, such as hope and faith.

The dialectic within the continua is a salient result of this study. Families' expressions throughout the interviews moved, for example, from openness to withdrawal, from comfort to insecurity. This dialectic between various experiences and behaviors is also described when dying patients are interviewed individually (20). However, Reimer et al. (11) described the situation of families at the end of life as a transition from living with cancer to dying of cancer. This transition was viewed as three chronological phases, which have to be passed through in order to prepare for death. In our study, it was not possible to clearly discern similar delimitations concerning phases over time. Instead, the possibility of a kind of repose for the families in their challenged life situation seemed to emerge from interplay of the continua.

Within the continuum being in affinity-being in loneliness, individuals try to find ways for enduring the life situation. The prominent feature of the continuum seems to be the struggle within the family over whether or not to talk to each other and share experiences. This ambivalence is a sign of the desire to protect themselves and each other from openly exposing their suffering. Sometimes talking was overwhelming and conversations between the family members did not take place. At the same time, it was precisely those moments of sharing which relieved suffering (21,22).

The tension within the continuum being in power-being in helplessness involves families' experiences of available resources to manage life. The level of understanding of the circumstances, and knowing what to do and how to do it seemed very important for families' well-being. Through their stories, families in this study acknowledged different areas of uncertainty about whether they could manage the life situation or not. When a family member is at the end of life, families often feel overwhelmed by all the changes they have to face and all the decisions they have to make (23,24).

Within the continuum being in continuity-being in disruption, families struggle with life and death, deficits, losses, and mortality. The struggle involves at least two possible ways of being: accepting or denying the present life situation. Acceptance of the life situation means not capitulating and becoming passive, but rather finding reconciliation with life and death. The assurance that life goes on with the next generation, and maintaining family rituals and interests is a sign of families' hope (25). Most families spoke of the fear of losing each other and how existential issues sometimes could not be spoken about. To open up for a deeper understanding of the complexity of what families have to endure, the narrative subjects of illness and various voices, as described by Frank (26), can be of help. When the losses and incoherence of suffering become so insurmountable that words are not enough and silence occurs, it can be the chaotic voice speaking. In the present study, this way of being in chaos was seen in the continuum of continuity and disruption. It is when patients are least able to express themselves that they mostly need to tell their stories and be listened to (22).

Some of the families spoke of an awareness of the losses that death can imply, but also a capacity to live in the present, and to accept the life situation and its uncertainties. Being a family under these circumstances is a great challenge, which is sometimes almost unbearable. At other times, it can be a source of growth and further understanding of life, and this is comparable to the quest voice, which reflects about self and others (26). It is only when one's own deficits are reflected on and recognized that they can be shared with others and, thereby, change how these deficits are experienced.

Strengths and Limitations

The strength of this study is the combined data collection through the use of illness stories, circular questions, and the drawing of genograms.
together with the families, which enabled a reflecting atmosphere to share experiences of the relationships in the family. The interview situations in this study also encouraged mutual reflection between family members and interviewers, and created new meanings and understanding of families’ life situations for both interviewers and families. The circular questions allowed a deeper conversation and generated intersubjective data about the family members’ thoughts, feelings, and behaviours inside and outside the family. The interviews were carried out in the families’ own homes, which was considered an advantage by both families and researchers. Presenting the results as poles of a continuum may limit a circular understanding and the small sample size may jeopardize the trustworthiness (27) of the results, even though they seem to be transferable to other families in the same life situation.

CONCLUSION

The challenge for health care professionals in contact with families at the end of life is to maintain receptivity for the comprehensive and multiple meanings of families’ experiences of being in the midst of living and dying. These families struggle to seek meaning in life, mortality, and death. The experience of being in a meaningful continuity with the past, present, and future, in human and spiritual relationships is important for family well-being. Opportunity for verbalizing and recounting the family illness stories with the guidance of health care professionals may provide new and deepened meanings about continuity and consistency in life and death. Openness and possibilities for sharing experiences with each other within the family offer a prerequisite for enduring each particular life situation. However, the desire to protect each other from suffering often implies withdrawal from conversations within the family concerning one’s own suffering. Health care professionals can invite families to conversations and create arenas for families to “speak the unspeakable”.

REFERENCES


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AUTHORS AND CONTRIBUTORS

The following list arranged alphabetically provides names and addresses of those persons contributing to this issue of the Journal of Palliative Care. Note that affiliations and current addresses may have changed since article

Ahn, Hyeong-Sik, MD, PHD
Department of Preventive Medicine
College of Medicine
Korea University
126-1, 5-ka Anam-dong Sungbuk-ku
Seoul 136-705, Korea

Barbera, Lisa, RSC, MD, MPA, FRCP
Department of Radiation Oncology
Sunnybrook and Women’s College Health Science Centre
2075 Bayview Avenue
Toronto, Ontario
Canada M4N 3M5

Bédard, Michel, PHD
Public Health Program
Lakehead University
955 Oliver Road
Thunder Bay, Ontario
Canada P7B 5E1

Benzin, Eva G., RN, BSN, PHD
Department of Health and Behavioural Sciences
Kalmarsjö University
S-391 82 Kalmar
Sweden

Brazil, Kevin, PHD
Department of Clinical Epidemiology and Biostatistics
Faculty of Health Sciences
McMaster University
105 Main Street East, Level P1
Hamilton, Ontario
Canada L8N 1G6

Chartier, Carole, MSW
Statistician and Program Director
Institute for Clinical Evaluative Sciences
2075 Bayview Avenue
Toronto, Ontario
Canada M4N 3M5

Fisher, Kim, RNP
Department of Obstetrics and Gynecology, Faculty of Medicine
University of Calgary
4th Floor, North Tower
Foothills Medical Centre
1441 29th Street N.W.
Calgary, Alberta
Canada T2N 4H9

Frid, Marianne, BPT, MSC
Lymphofemtotagningen, RTA
Universitetssjukhuset i Lund
221 85 Lund
Sweden

Friedrichsen, Maria J., RN, PHD
Department of Welfare and Care
Palliative Care
Faculty of Health Sciences
Campus Norrköping
601 74 Norrkoping, Sweden

Hagen, Neil, MD, FRCP
Division of Palliative Medicine
Tom Baker Cancer Centre
1331 29 Street NW
Calgary, Alberta
Canada T2N 4N2

He-Ling, Chang, MD
Department of Family Medicine
Buddhist Tzu Chi General Hospital
No. 707, Sec. 3, Chung Yang Road
Hualien, Taiwan

Heim, Bob, RTI
Rockyview Dispensary
1011 Glenmore Trail Southwest 110
Calgary, Alberta
Canada T2V 4R6

Jo, Min-Woo, MD, PHD
Department of Preventive Medicine
College of Medicine
University of Ulsan
388-1, Pungnap-dong
Songpa-gu
Seoul 138-736, Korea

Johansson, Karin, RPT, PHD
Lymphoedema Unit
Lund University Hospital
22185 Lund, Sweden

Justice, Christopher, PHD
St. Joseph’s Health System
Research Network
1323 Governors Road
Dundas, Ontario
Canada L9H 5E3

Kelley, Mary Lou, MSW, PHD(CAND.)
School of Social Work
Lakehead University
955 Oliver Road
Thunder Bay, Ontario
Canada P7B 5E1

Kim, Kyong Uoon, RN, PHD
Department of Nursing
Seoul Women’s College of Nursing
287-89, Hongjaedong
Seodaemun-gu
Seoul 120-742, Korea

Krueger, Paul, PHD
Department of Clinical Epidemiology and Biostatistics
Faculty of Health Sciences
McMaster University
105 Main Street East, Level P1
Hamilton, Ontario
Canada L8N 1G6

Lee, Junyoung, PHD
Department of Preventive Medicine
College of Medicine
Korea University
126-1, 5-ka Anam-dong Sungbuk-ku
Seoul 136-705, Korea

Lee, Sang-Hi, MD, PHD
Department of Preventive Medicine
College of Medicine
University of Ulsan
388-1, Pungnap-dong
Songpa-gu
Seoul 138-736, Korea

Lim, Huey-Wen, MD
Department of Family Medicine
Buddhist Tzu Chi General Hospital
No. 707, Sec. 3, Chung Yang Road
Hualien, Taiwan

McAiney, Carrie, PHD
Department of Psychology
Lakehead University
955 Oliver Road
Thunder Bay, Ontario
Canada P7B 5E1

Park, Hye-Ja, RN, PHD
Department of Nursing
Medical College
Pochon CHA University
222, YaTap-Dong, BunDang-Gu
SeongNam City
Kyunggi-Do 463-836, Korea

Pastor, Lawrence, BA, MD, MSC, FRCP
Institute for Clinical Evaluative Sciences
2075 Bayview Avenue
Toronto, Ontario
Canada M4N 3M5

Ruscio, Lori A., PHD
School of Aging Studies
Division of Geriatric Medicine
Center for Hospice, Palliative Care and End-of-Life Studies at USF
University of South Florida (MHC 1300)
4202 Bruce B. Downs Boulevard
Tampa, Florida 33620

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Saveman, Britt-Inger, RNT, PhD
Department of Health and
Behavioural Sciences
Kalmar University
SE-391 82 Kalmar
Sweden

Schonwatert, Ronald S., MD
LifePath Hospice and
Palliative Care, Inc.
Center for Hospice, Palliative Care
and End-of-Life Studies at USF
3010 West Azeele Street
Tampa, Florida
USA 33609

Singer, Yoram, MD
Division of Health in the Community
Faculty for the Health Sciences
Ben-Gurion University of the Negev
P.O.B. 653
Beer-Sheva
Israel

Stiles, Carla, RN
Alberta Cancer Board Palliative
Research Initiative
Tom Baker Cancer Centre
1331 29 Street NW
Calgary, Alberta
Canada T2N 4N2

Strang, Peter, MD, PhD
Research Unit
Stockholms Sjukhem Foundation
Karolinska Institute
Mariebergs, 22
Stockholm 11235 Sweden

Su, Fu-Hsiung, BMBS
Department of Family Medicine
Tao-Yuan General Hospital
1492, Jaung-Shan Road
Tao-Yuan, Taiwan, R.O.C. 330

Syrén, Susanne M., RNT, MSc
Department of Health and
Behavioural Sciences
Kalmar University
SE-391 82 Kalmar
Sweden

Szala-Meneok, Karen, PhD
Department of Clinical
Epidemiology and Biostatistics
McMaster University
50 Main Street East
Hamilton, Ontario
Canada L8S 4L8

Taniguchi, Alan, MD
Division of Palliative Care
Department of Family Medicine
Faculty of Health Sciences
McMaster University
1200 Main Street West, HSC-2V9
Hamilton, Ontario
Canada L8N 3Z5

Tsai, Shih-Tzu, MD
Department of Family Medicine
Buddhist Tzu Chi General Hospital
No. 707, Sec. 3. Chung Yang Road
Hualien, Taiwan

Vohra, Julie Uma, MSc
St. Joseph’s Health Research
System Network
105 Main Street East, Level P1
Hamilton, Ontario
Canada L8N 1G8

Wang, Ying-Wei, MD, PhD
Department of Family Medicine
Buddhist Tzu Chi General Hospital
No. 707, Sec. 3. Chung Yang Road
Hualien, Taiwan

Yoon, Seok-Jun, MD, PhD
Department of Preventive Medicine
College of Medicine
Korea University
126-1, 5-ka Anam-dong Sungbuk-ku
Seoul 136-705, Korea

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Dr. Herbert’s attribution should have read:

DONALD HERBERT, Department of Radiology, COM Biostatistics and Epidemiology
Core Unit, University of South Alabama, Mobile, Alabama, USA