

# Exploring Empathic Communication Among Families During Hospice: A Conceptual Model and Principles

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## **Abstract**

This position paper examines excerpts of interview transcripts that explore empathetic communication among family and friends during end-of-life hospice care. Examples show how empathy can be expressed 1) outwardly as a desire to understand “the other”, 2) inwardly, or as a desire to be understood by others, 3) self-reflexively, in which a new understanding of the self in the present or future is enabled by a detour of empathizing for the other, 4) or dialectically, in which symmetrical empathy and self-reflexivity can result in the co-construction of a new shared meaning of the past or present. This paper hypothesizes that limitations to ability to empathize might be overcome through a reversal of the directional flow of empathy, in which a better understanding of the self might result in a better understanding of the other, or vice versa. Therefore, empathy sensitive designs need to account for overlapping and multi-direction flows of empathy, including a critical look at the self.

## **Author Keywords**

Empathy; Hospice; Communication; Self-Reflexivity; Anthropology; User-Centered Design

## **ACM Classification Keywords**

H.5.2. User Interfaces: User-Centered Design

## **Introduction**

The concept of empathy is often associated with moments of compassion, commiseration, appreciation, understanding, and acts of altruism, particularly in the field of psychology where empathy is a phenomenon of study for perception, communication, collaboration and learning [1] [2] [3].

A common sense definition of empathy is “the power of understanding and imaginatively entering into another person’s feelings” [4]. In this definition, the ability to empathy with another person entails more than understanding others from an intellectual or rational basis but also invokes creativity and affect from the empathizer. Empathy is a creative action when the empathizer imagines, or goes beyond their current point of view or experience (i.e. imaging or remembering themselves in the same or a similar situation). The creative aspect of empathy also translates on an affective dimension when the relating or imagining occurs at an emotional level (i.e. sharing someone’s excitement or disappointment).

## **Methods**

This paper reports on semi-interview data collected over a 10-month period with family and friends of recent deceased individuals (n=16)<sup>1</sup>. The purpose of the study was to explore instances of intergenerational communication with the aim of eliciting design principles for information communication technologies that enhance presence, communication, and comfort among intimate groups near the end-of-life. The data was coded inductively to identify recurring topics, which were then clustered into key themes (not presented in this paper but see [5]).

Although empathy was not an intended topic of the interview, several examples of empathy did emerge in the data that point to ways in which the desire to understand or be understood can be supported through computer interface design. Together, such examples provide a deeper level of context, situated in interpersonal human communication and intimacy than basic research in psychology provides in the present.

## **Analysis**

The remainder of this paper will present 3 different examples of empathy selected from 2 interviews (referred to henceforth as cases). Each example is concluded with a short analysis, prior to an overall discussion and conclusion.

### **Case 1**

#### Context

Darline was an articulate and assertive woman in her mid 50’s. She was one of the last participants recruited to our study and contacted us after hearing about our study from the Hospice residence she and her family selected for her father’s last weeks of life, after suffering from lymphoma and deciding not to receive further treatment. As an organized and assertive person, Darline found herself in a central coordinating role during her father’s hospice care. As such, she played a major part in locating and selecting an appropriate hospice residence for her father, along with her brother sister, and elderly mother. For Darline, it was important to find a hospice that would provide her father and family with a home-like environment that she, and her family, could have confidence in and feel comfortable entrusting their father’s care with. After much stress from visiting at least three hospices in the area around her, Darline was finally select Treetop Hospice, which gave her a great sense

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<sup>1</sup> All names, locations, and minor elements of the backstories used in this interview are pseudonyms and obscured for the purpose of anonymity and may not correspond with the pseudonyms or backstories used in previous papers published using the same dataset. All examples reported in this paper come from the Canadian context.

of comfort and closure during and after her father's passing; knowing he was well cared for in a pleasant and supportive non-institutional environment.

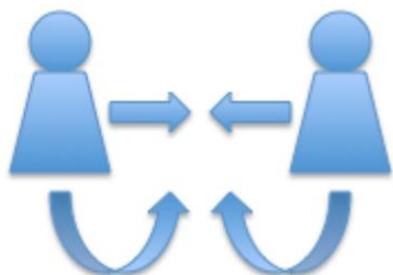


Figure 1 - Empathic Co-Constructed Meaning

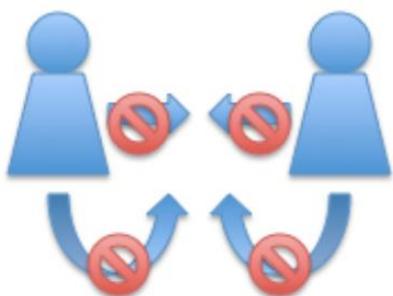


Figure 2 - Breakdowns in Empathy

#### Key:

E = Empathizer

O: Other

#### Example 1 – A Desire to Be Understood by Others

When Darline was to describe communication challenges she experienced when trying to find a hospice, the example she chose to speak about emerged not from the experience of shopping around for a hospice locale itself but rather from the interpersonal relationships she had with her brother and mother. Darline's case provides a nuanced look at overlapping directional flows of empathy and that limits to one's ability to empathize do exist.

Darline described the impact of being the oldest of her siblings and how her brother might not have appreciated the pressure Darline felt when told things in confidence. After an initial round of treatment for his cancer, Darline's father decided to decline further therapies aimed at curing his cancer and instead desired to die with dignity. Darline described how her brother confided in her that he blamed her mother for their father's decision. Darline's brother believed their father should continue to fight the cancer and he blamed their mother for accepting their father's decision prematurely because she was afraid of being a primary informal caregiver should her husband continue to fight.

Darline: Um, my mom had said to us, you know, if your dad comes home, he has to have chemo and radiation. You know, I'm going need help. I can't do this all on my own. Right? And I think my brother thought that my mom did not want [our father] to come home [from the hospital]. **So, my brother is kind of a different breed. He doesn't show his emotions. He's not very close. So, um, we had a difficult time with him. Like, he did not spend the time with my dad that my sister and I did.** And I had a hard time with that because being the

oldest I guess everybody confides in me. But, **I knew at the time he wasn't working but my parents didn't know that. And to me he had all the time in the world to spend with my dad, when my sister and I both took time off. Right?**

#### Analysis

Darline felt like her brother blamed their mother because he was unable to realistically empathize with the stress and overall disruption in day-to-day life that their father's continued treatment would require. Darline's brother was unable to empathize with their mother or Darline because he was unable to step out of his

own perspective or consider the needs or impacts of their father's continued treatment on others. This was exemplified by the way Darline felt her brother failed to recognize the sacrifices Darline and her sister were making to participate in their father's care in stark contrast her brother's lack of participation despite being unemployed. In this example, Darline's critique of her brother indicated the opposite direction of empathy as expressed in Example 1 (Nina and Mira). Instead of seeking to understand the situation of the other, Darline wished her brother could better understand the position of her father, mother and sisters. That is, she expressed a desire to be empathized with rather than a desire to empathize herself.

### Example 2 – Empathy as Interpreting Others

Darline also expressed the challenge of empathizing with her mother while shopping around for their ideal hospice. Interpreting her mother's behavior during these visits required Darline to actively empathize in order to make sense of the situation and recount it during the interview.

Darline: So my sister and I proceeded to make an appointment to go, and we took our mom. And the first place we went to visit was Happystream Hospital's palliative care ward. **And my mother had a real hard time with this, Robert. She did not want to deal with what was happening.** So, she said to us, she said, I think I'll be in the car while you go in. And I said, "No Mom, this is a decision that you have to make. So come with [us]." My mother, when we actually were speaking with the social workers there **my mother had a complete meltdown. She fell asleep. She just shut down.** Right? And I was so embarrassed, Robert, but **I guess it was just her way of dealing with it. She just tuned herself out.**

### Analysis

In the above excerpt, Darline actively empathized with her mother in retrospect, interpreting her mother's inappropriate falling asleep during the hospice introduction, as a mental breakdown and coping strategy. In this example, Darline has to actively imagine and move beyond her own feelings of responsibility and embarrassment, in order to explain why her mother reacted the way she did. This example differs from Example 1 (Nina and Mira) by the way Darline expresses a subtle sense of certainty in her interpretation of her mother's behavior compared to Nina, who described limitations to her ability to empathize marked by a point in time, during the dying process, at which she could no longer empathize. Unlike Nina, Darline's ability to empathize was not marked by a point where she no longer understood or did not express the need to validate the impressions she garnered during the initial experience.

## **Case 2**

### Context

A colleague who felt Marge's story made her a good candidate for our interview referred Marge to us. Marge was in her mid 60's and had lost her mother a few years prior to the interview of old age and had acted as the primary caregiver while her mother was in a palliative care facility. One of the most positive aspects of the hospice process for Marge was the ability to get to know her mother in a new way and bond further because the hospice scenario provided the context for her mother to retell her life's story.

### Example 3 –Empathy as Co-Construction of Meaning

As a pass time in the palliative care setting, Marge's adult daughter bought a book with 1001 questions to ask someone about their life. When asked to describe her ideal ICT for the hospice setting, Marge described the book and the positive impact it had on her hospice experience, which she believed could be enhanced through access to the internet via smartphone or tablet technologies.

Marge: ...what the book does is, **it invokes memories** for, for instance for my mom. It invoked memories of her childhood, her relationship with her parents. Um, special things that happened. It was an absolutely wonderful event, shall I say, of discovery for all of us. Because Mum talked about, as a child, the things that her mom and her dad did for her. How she met her husband, my dad. Talking about her having the children, and their emotions around all of that. It even went so far as to talk about the dress of the day. What their leisure activities were. **So, it was a real discovery.** It was wonderful... It was quite emotional. Because my mother as we said was very lucid. And was providing real visual pictures for us. So it was emotional in the way that **you were very happy, happy for this person that had had this life.** And there were other times in her life story. My dad was overseas for five years. Mum was on her own. She had my brother, but she was on her own. And lived with my grandparents. And then she talked about. **So that was kind of emotional in a way of crap, I can't even imagine. You know? We have no concept.** As in she talked about the loss of her mum, and how devastated she was. And she had, my mum had, miscarried a couple times. **And I guess I knew that in the life story, but until this, at this time when we were having this discussion. Now I'm an adult with grown children of my own, and that kind of thing. You really start to understand the impact on people.** So there was, yeah there was sad stuff. But most of it was very, very positive emotionally.

### Analysis

This final excerpt provides another example in which empathy can become self-reflexive, this time not necessarily for reconfiguring an understanding of the self but of the other through the self. This is expressed through Marge's discussion of how although she knew many of the stories shared as a result of the book, hearing these stories again later in life, and in reflection of Marge's own experiences of growing up, getting married and having children of her own; she was able to find a new understanding of her mother's life that she wasn't able to imagine in her own youth. This example provides a potential indication for how limitations in one's ability to empathize can be overcome through the passage of time and with further experience, indicated how what was once unimaginable to Marge in the past, became knowable, meaningful, and perhaps emotionally positive in the present.

### **Discussion**

The excerpts from the hospice data presented here demonstrate how empathy, in practice, is multi-directional. Example 1 shows how empathy could be desired inward from others by a desire for others to step beyond their own perspectives and experiences and the impact of another person's limits to empathize. Example 2 showed that empathy could be a source of certainty in order to make sense of confusing and difficult situations. Example 4 provided an alternative example of the limits of one person's ability to empathize where thinking of the other resulted in a better understanding of the self and the needs of the empathizer rather than the person being empathized with. Lastly, example 5 showed an instance in which previous limitations in the ability to empathize were overcome over time. Example 5 provided an example where a new of understanding of the other was developed

through a new understanding of the self. Example 5 points to the potential for empathy to facilitate co-construction of meaning if Marge's own mother experienced a new self-reflexive understanding of herself – although this hypothesis goes well beyond what can be supported by the data.

### **Conclusions**

The position paper argues that empathy is a multi-directional concept. Empathy can be expressed as a desire or ability to imagine or understand the experiences of another (outward). Empathy can also be desired from other people, as a need to be understood rather than understand (inward). Empathy can also be expressed self-reflexively when imagining or trying to understand the current or future position of the other results in new understandings of the self (self-reflexive). Supporting expressions of empathy via technology also has the opportunity to result in new-shared understandings and the co-construction of meaning. This paper has argued that limits do exist to people's abilities to empathize based on time and experience but that these limits are not fixed and can be overcome by time, further experience, or a reversal in the directional flow of empathy via a self-reflexive detour vis-à-vis the self.

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