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Shortened version of the title: The Need for Dialogical Encounter

Abstract:

In this article a Christian couple narrate their experience of the medical system during the pregnancy, birth and death of their severely handicapped daughter, focusing on key ethical decisions relating to pre-natal testing, DNR orders and withdrawal of treatment. The nature of the modern pluralist, consumer-patient oriented system is reflected upon and a resulting sense of isolation described. Using the work of literary theorist Mikhail Bakhtin, a paradigm of “dialogical encounter” is proposed as a way of minimising the isolation and stress due to life and death decision making. Some practical ways of implementing such a dialogical encounter are suggested.

Key words: Chromosomal abnormality; decision-making; disorientation; Bakhtin; dialogue.

Introduction

For parents of so-called handicapped children the sense of dislocation and isolation can be overwhelming. In her well known essay, Welcome to Holland, Emily Perl Kingsley (1987) uses the metaphor of awaiting the arrival of a child as excitedly preparing for a vacation to Italy and instead arriving in Holland: "What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy." Italian guide books have been studied. Italian phrases have been learned. Trips to the Coliseum, Venice, and Michaelangelo’s David have been planned. All that must now be set aside. A new guide book must be found. A new language must be learned. New
plans must be made. All of this involves grief and can be very overwhelming for parents of ‘handicapped’ children.

In the following paper, we, as Christian parents of a severely developmentally delayed and physically challenged child, narrate our experience of dislocation and isolation in the context of negotiating various medical decisions within the modern health care system. After describing our experience, we shall argue that even though the system gave us space to make decisions from our own faith tradition, it failed to engage with the particularity of our Christian beliefs and thus added to our sense of dislocation and isolation. The emphasis on patient autonomy and choice means that in order for medicine to be ethical it must provide patients only with means and let the patient, or in our case the patient’s surrogate, supply the ends. The result of this essentially consumerist model is that we had no-one to assist or partner with us in the hard work of our ethical decision making. We will propose that a model of "dialogical encounter" can be applied in situations such as ours in which the medical system and patients/parents with faith commitments can work in partnership and thus minimise the burden of choice.

**Context**

In terms of our personal context, we write biographically as an academic theologian (Mark) and counsellor/educator (Ruth). At the time, even though Mark was only in the first few years of his MDiv studies we realise that, compared to the general population we were highly educated, resourceful and self-sufficient. Ruth had a PhD in Counselling Psychology and Mark had been teaching law for four years at a Scottish university. Our experience may have been overall positive, but we wonder how much this was due to our resourcefulness and capacity for complex decision-making.
Both of us grew up in families and environments which gave us strong Christian foundations for ethical decision making. From our earliest years our Christian faith had taught us that human life is a sacred gift from God, and so abortion was never an option. Our implicit ethical beliefs were well expressed by Hui (2002, 366):

[We] view parenthood as a vocation and children as gifts from God to be embraced whether they are normal and bright or handicapped... [we] consider the sanctity of life as weightier than the quality of life... the supreme value of human life.... even when it serves no apparent useful purpose. This is because [we] believe that those afflicted and handicapped with genetic disorders can still enjoy meaningful lives as persons in all their relations with God, the people around them and the rest of creation. ... Society as a whole may reject those who fail to meet the so-called decent minimum.... Christian tradition holds that all human beings are created equal as the image of God.

In terms of the medical context, even though beginning in Aberdeen, Scotland, the majority of our experience took place within the health care system of British Columbia, Canada. Our understanding, confirmed by our experience, is that the Canadian system operates out of commitment to pluralism, honouring diversity and the autonomous choice of the patient. This is in contrast with the more paternalistic European health care systems (Carnevale 2013). Carnevale (2013) sets out the difference between the French and Canadian medical system in relation to their "social imaginary." He notes that in France "it has been commonplace for physicians to take decisional responsibility for determining whether or not to continue with resuscitative care for children" (90). In contrast, the Canadian Paediatric Society 2004 guidelines state that, "for children who cannot give consent themselves, parents should be responsible for granting permission for treatment, giving great weight to the expressed views of the child where possible" (91). For Carnevale, these guidelines are consistent with the prevailing norms regarding the care of children in North America: parents are normally the surrogate decision makers for children without capacity to
make decisions; and such parental decisions should be made in the "best interests" of the child. In North America these norms are legally formalised. Carnevale notes that, "Although there may be instances of physicians acting in a paternalistic manner, this is frequently denounced either through hospital complaints procedures, legal proceedings, or through public media" (2013, 91-92). These systems thus recognise the "quasi-absolute parental authority" in terms of the care of children.¹

In relation to the role of the physician Carnevale (2013) notes that whereas French physicians see themselves in terms of having a 'noble' social status, "Canadian physicians have been professionalised into a form of entrepreneur with whom a 'consumer' establishes a contractual relationship... The 'consumer-parent' sometimes seeks a second opinion or contests the quality of the physician services that were provided" (92).

Our experiences confirms this understanding of the centrality of parental authority in the context of a pluralist medical system. We never felt forced by medical staff to take a particular course of action when a number of options were available. We were given an open space in which to make decisions based on our own faith perspective, however the space at times felt like a vacuum leaving us on our own in great distress with our decision-making facilities pushed to their limits. Like a customer who is "always right" the burden of decision making weighed heavily on our shoulders despite our own limited medical knowledge.

The Story Begins

In the fall of 1994, full of evangelical idealism, we left the security of our jobs, family and promising careers in Scotland and headed to Canada to study theology at Seminary. To add to our excitement

¹ Bahus and Førde (2011) note the differences between states in terms of how they understand parents' decision-making powers and the child's best interests. They name Canada as a state that gives maximal authority to parental judgement and decision-making.
Ruth was pregnant with our first child. In Scotland we had ultrasounds at 12 and 18 weeks which led to no reasons for concern. We were also given the opportunity of a standard serum screening test for the likelihood of Down’s syndrome, or other genetic abnormalities, which we refused. If abortion was not an option then there was simply no point in screening.²

When Ruth went for her first pre-natal check-up in Vancouver she was in her 35th week of pregnancy. The initial reaction of the family doctor was that Ruth “looked small”. Dates were recalculated and the doctor concluded that Ruth was 33 weeks gestation. Ruth was therefore sent for another ultrasound to verify the dates for delivery planning purposes. This time the verdict was that Ruth was only 31 weeks. It seemed strange that the initial calculations of the due date (done in Scotland) could be so inaccurate. Unbeknown to us, this confusion was the beginning of our sense of feeling lost and alone in unknown territory.

A week after the ultrasound Ruth received a call from the family doctor to talk about the results, and to inform her of another concern: an abnormality in the baby’s brain had been detected. The space between the ventricles was bigger than it should be, which may mean an abnormality in the development of the spinal cord resulting in the baby having hydrocephalus. On the phone Ruth was stunned by the news, not knowing what to say or ask. She relayed the news to Mark. Both of us were overwhelmed. We were alone in a unknown territory, getting used to a new medical system with its own set of rules, without immediate family support or friendships. Now we were facing weeks of anxiety before the birth of our first child.

² Brian G. Skotko, currently Co-Director of the Down Syndrome Program at Massachusetts General Hospital, has undertaken significant research the impact of testing for Down syndrome and how physicians deliver diagnosis. He cites research in which the data showed that 92% of women who received a definitive prenatal diagnosis of Down Syndrome chose to terminate their pregnancy (Skotko 2009). Skotko argues that there is a general failure on the part of physicians to communicate the overall positive experiences of parents with Down syndrome children (Skotko, Levine, and Goldstein 2011; Skotko 2005; Skotko 2009).
A few days later we met with our family doctor again. She seemed very nervous and wasn’t able to answer our questions and suggested we see a specialist. A week later we found ourselves at Vancouver Women’s Hospital. After a very long wait we finally saw a radiologist who explained that there was a blood clot in the baby’s brain and the ventricles had extra fluid in them. Two doctors were called; the first was going to be our Perinatologist (Dr. A). The second did more ultrasounds and pointed out another possible problem: the corpus callosum was missing which could mean permanent brain damage. We were in shock. A second opinion was sought from a specialist neuroradiologist who performed another ultrasound and reassured us that the corpus callosum was all there and that the blood clot was also not a significant concern. We were overwhelmed and confused with such conflicting accounts of the baby’s condition.

Dr. A then took a detailed family medical history, during which we raised the original concern over the baby’s size. He seemed unaware of this concern. After considerable time tracking down the necessary paperwork, he suggested that Ruth be hospitalized immediately since the baby was classified as having Intrauterine Growth Retardation (IUGR). The immediate and pressing concern was now the baby’s lack of growth and possible distress. The abruptness of this new piece of news created an overwhelming sense of disorientation. After five hours of consultations with various specialists all shedding new and often contradictory light on our baby’s condition, we were emotionally and physically drained.

**The Hospitality of the Hospital**

The next day Ruth was admitted to Women’s Hospital. The first day was consumed with medical histories, blood works, ultrasounds and fetal heart monitoring. A genetic counsellor and a medical

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3 We felt that this family doctor was out of her depth with our case so we changed family doctors the following week. On the recommendation of our Pastor’s wife, we registered with an older Christian GP who we felt much more comfortable in her care, by not only sharing our faith but also by her maturity and calm manner.

4 To preserve anonymity and respect confidentiality we have not used anyone’s name apart from our own.
geneticist explained to Ruth the possibilities of the baby’s growth being retarded due to a genetic abnormality. There was a 10% chance of the baby having either trisomy 13 or 18, in which case the baby’s survival chances would be minimal; and also the chance of trisomy 21, which we discovered was the medical term for Down’s syndrome. Here we were, knowing that we would not be arriving in Italy as expected. We were entering a whole new and overwhelming medical world with a whole new bewildering language.

Ruth’s way of coping was to take copious notes of all the medical terms and try to use them in all her conversations with the medical practitioners. With Ruth having a PhD in Psychology the medical forms had her listed as Dr. McConnell. We wondered if this had implications on how she was treated by the medical professionals. On the positive side, she may have been perceived as a peer so the medical staff displayed more openness to fuller conversations about the complexity of our unborn child’s condition. On the negative side, this possible assumption on the part of the doctors that Ruth possessed more understanding than she actually had, left her feeling very overwhelmed. Once left alone, she processed, grieved, became perplexed and wrote down more questions.

On the second full day of bed rest Dr. A gave us some possible explanations for the blood clot and the baby’s size. Certainty could be gained with fetal blood cord sampling. We asked about the associated risks and were told that it may induce early labor, which would mean having to do an emergency cesarean section as the doctor did not recommend a vaginal delivery due to the blood clot in the brain. He also raised the possibility of an amniocentesis which would tell us about chromosomal abnormalities; the results would only come back in 3 weeks which would be too late as a planned caesarian delivery was scheduled for 2 weeks time (at 38 weeks gestation).

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5 According to Hui (2002, 348) screening procedures carry considerable risk. It is a standard assumption that one in 200 cases screening will result in spontaneous abortion. Citing Clark and DeVore (1989, 1035-1037), in a large series of amniocentesis, the rate of miscarriage was reported to be 1.6% and the foetal damage without miscarriage is reported to be 0.3%.
We were given until the following morning to make up our minds about these tests. The means was offered to us; the end result was ours to figure out.

We felt a sense of panic due to the weight of the decision and the time pressure. Our minds spun with many questions. We decided to get out of the hospital room and go for a walk. On our way we ‘bumped’ into Dr. A’s supervisor. We weren’t empowered enough to seek a second opinion but it felt like the second opinion ‘found’ us. His opinion was reassuring: rather than being a 10% chance of a chromosomal abnormality he felt it was more likely to be about a 2% chance. With our anxiety lessened, we decided against any invasive interventions that carried risk to our unborn baby. Our strategy was to hope and pray for the best outcome and go with a planned caesarian section in two weeks time.

When we did make our decision we found the staff very supportive. This was especially the case with a Christian nurse who spent time praying and crying with Ruth. The next few days involved more fetal heart monitoring and ultrasounds. On the eighth day at around midnight, Ruth started vomiting accompanied by diarrhea. The next day it was concluded that Ruth’s suspected stomach flu cramps were actually contractions. Unable to stop the contractions, the medical staff made preparations for an emergency caesarian section. A few hours later Bethany Joy was born, weighing 4lbs 7oz. After delivery the pediatrician took her away to suction her lungs; finally, being satisfied with her breathing, Ruth was handed our new child. We held her for a few minutes then the nurse took Bethany to the neo-natal nursery where she was put in an incubator on oxygen.

The following days we were overwhelmed with emotion. Bethany’s breathing and feeding were not good. We were given updates by the pediatricians on all the tests they were conducting: the blood clot would probably dissolve itself; they did find an abnormality with the corpus callosum, although the implications of this were uncertain. Slits were found in her retinas and they were not sure about
the condition of her heart. The combination of these factors suggested a chromosome abnormality. Her long-term prognosis was uncertain.

On the third day after her birth we were told the preliminary chromosome results: a deletion of the 5th chromosome. Without medical training this meant little to us. Mark took it upon himself to locate the hospital library and researched all he could about 5th chromosome abnormalities. The “guidebooks” of this foreign land he found were shockingly different from “baby books” he had so far been reading.

The next day however, we were told by a genetics specialist that the deletion was actually in the short arm of the 3rd chromosome, referred to as 3p-. We were told that her condition was extremely rare with only two other recorded cases of 3rd chromosome deletions, and even these were not exact matches, and so there was no available data about her long term prognosis. Mark went back to the library to research but found nothing. We felt powerless and left alone in unknown territory.

**The Daily Grind - Fighting for Life or Staving Off Death**

Over the course of the first year of Bethany’s life there were multiple visits to specialists. We were trying to get answers to a variety of questions: Why can’t she suck, swallow and breathe? Will she have to be fed by a tube all her life? Will she be able to walk? Or talk? Can she hear? We also entered into a ‘living grief’. Emde and Brown (1978 as cited by Barnett et al, 2003, 187) note that parents of handicapped children enter a process similar to bereavement. As Barnett et al, (2003, 187) state: “physically, their baby is not lost; he or she is right there with them. Instead, these parents are grieving for their hoped for child – the child they were expecting who never arrived.”
The daily care of Bethany was complex: suctioning when she got very congested and choked on her mucous; nasogastric tube feeding; giving medications half an hour before a feed to reduce reflux.

Ruth had to be taught infant CPR before Bethany was released from hospital, as she frequently had apneas and cyanosis. We needed to take shifts throughout the night to monitor Bethany’s breathing and make sure she didn’t choke on night feeds because of her lack of cough reflex and the inability of her brain to co-ordinate sucking, swallowing and breathing. Her fragile immune system meant regular visits to the paediatrician for recurring kidney infections and colds/excessive congestion as well as routine changing of her nasogastric feeding tube. After a couple of months the paediatrician explained that Bethany’s feeding problems may not be something she would outgrow and were actually related to her neurological impairment. We grieved this and decided to get a gastrostomy tube inserted as a more permanent solution to her feeding.

At the end of Bethany’s first year, despite her many limitations and the daily “living grief” we experienced, we were starting to feel that Bethany was doing as well as could be expected with her condition. We felt things were stabilising and we were able to enjoy Bethany in all her uniqueness.

**The Beginning of the End – Do Not Resuscitate**

When Bethany was nearly 13 months old, Ruth noticed that she was struggling to breathe and took her to Emergency. On admission the doctor immediately realized that there was something seriously wrong. Bethany’s oxygen saturation level was down to 50%. Being unresponsive to additional oxygen, respiratory therapy was called and two nurses ran with her to a treatment room. Intensive Care was then called with three nurses taking blood, suctioning her, putting an oxygen mask over her and manually pumping oxygen into her. Bethany was then intubated and taken to ICU.

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6 On the first night that Bethany was at home she choked and stopped breathing; we panicked and called the emergency services. Before they arrived, Ruth’s mother, a trained mid-wife, got Bethany to breathe again by folding her in and out like an accordion.
In the midst of all this Ruth was asked what to her was a shocking question. She later wrote in her journal:

[The doctor] asked me whether we had a DNR order written up - a Do Not Resuscitate order. At first I did not know what it meant and when the doctor explained it, I was shocked by the question. I said that I wanted her treated as proactively as possible, like any other child. I wasn’t prepared to just sit back and let her die. It took some time for the truth of the situation to sink in but I started to realise that I have just faced a terrible scenario! We were faced with the awful choice of intervening to help her through this respiratory crisis or to not intervene and let her suffer and possibly die. Some may see the death of a handicapped child as a relief from a great burden but I would not see it like that.

It was as if Ruth’s moral universe, which valued life whether handicapped or not, had been turned upside down.

Over the next two weeks Bethany continued, sedated, on a ventilator in ICU; she was diagnosed as having a respiratory virus which in most healthy children would be experienced as a common cold. During this time we went through the ups and downs of seeing her make progress, then deteriorating with more complications developing.

**Struggling to Live or Struggling to Die?**

On day 10 Bethany took a turn for the worse, developing septicaemia. A meeting was arranged with the doctors and nurses involved in Bethany’s care. We made a list of questions to bring to the meeting. At the meeting her primary physician explained that Bethany was deteriorating rapidly and
her chances of recovery were very small. We had a choice to make: either we could wait until the bitter end which might result in Bethany’s heart stopping or her lungs giving way or we could turn the ventilator off, and hold her, quietly and peacefully, as she passed away.

The main question that we needed an answer from the medical professionals was, “Is she struggling to live or struggling to die?” This question came from an essay that Mark wrote in an Ethics class at Seminary on the topic of “Selective Nontreatment of Handicapped Newborns”. It focused on the case of a Down’s syndrome new-born child with oesophageal atresia which meant that any food taken orally would cause choking. The parents had refused treatment, and despite a late court judgement initiated by the hospital, the baby had lain in hospital for six days until starving to death.  

Little did we know how pertinent and timely Mark’s essay would be in helping us developing the key question we posed to the doctors in the meeting. For us, even though formulated from within our particular moral framework, we saw the question as a medical one established by diagnostic and prognostic assessments. Despite the fact that doctors are generally “terrible at prognosticating death, [but] usually are able to accurately predict when someone is actively dying” (Bishop 2011, 10, citing Kaufman 2005), ours were surprisingly and frustratingly hesitant to answer our question. It was as if they didn’t want to take responsibility for the decision, or engage with our ethical decision making or faith perspective. Once again we were left on our own, isolated and disoriented. This was a parental decision, not one for medical staff.

Nevertheless, for us, it was a medical evaluation, and so, with considerable effort, we pushed until we got an answer. In the end each member of the medical team confirmed that there was little possibility of recovery, unanimously asserting that she was struggling to die. We needed this confirmation from the qualified medical staff. We decided to turn off the ventilator. After 13 months

7 The case was not an isolated one. For details of the case and other similar cases see Gustafson (1998).
of holding this small frail life in our hands, taking care of her to the best of our abilities, advocating and fighting on her behalf, making decisions for the sake of life, we now had to let her go and watch her die, holding her in our arms as we did so, with many tears.

**Reflections**

In reflecting on our experience of the medical system over an intense and difficult 14 month period we are very thankful for the care that was shown to us and to Bethany. We have great admiration for the medical staff that we encountered and deeply appreciate the resources of the medical system. In many ways, despite all we went through, our overall experience was positive. Despite this, we sensed there was a subtle failure of the system in relation to engaging with our particular faith perspective which served as a basis for our ethical decision making.

As noted from our narrative there were a number of occasions when we experienced a sense of bewilderment as we tried to comprehend complex medical information, and new medical circumstances, and then make literal life or death decisions. In these key moments we felt very much left on our own. Our sense is, given the pluralistic context of the Canadian health system and the presumption of patient autonomy and parental authority, this would not be an uncommon experience. At a certain point the system withdrew from engagement and, in some respects, gave up responsibility. The system was unwilling, or perhaps even unable, to give us real, substantive guidance. It could be said that the system was respectful of our religious and moral beliefs, but the respect that was offered ironically added to our sense of isolation. And so, we felt the additional burden of having to work out our own answers.

Our experience would also fit with Carnevale’s (2013) comments about Canadian physicians being professionalised into a form of service-provider who deals with customers. The medical system may
provide a service, but it is the customer who has to make the choice and also determine the ultimate reasons for the choice. This was particular felt by Ruth when she was asked whether Bethany had a DNR order. Although we realise the importance and seriousness of the question, in some ways it felt like the equivalent of saying "What was your order again? With fries?" For Ruth it felt jarring and distressing.

The withdrawal of responsibility, and the associated consequences, has been noted by others. Franz Ingelfinger, a past editor of the New England Journal of Medicine has stated, "A physician who merely spreads the [options] in front of a patient and says, 'Go ahead and choose, it's your life,' is guilty of shirking his duty,... the physician should recommend a course of action... and must take the responsibility, not shift it on to the shoulders of the patient" (cited in Wellesley and Jenkins 2009, 975). We believe that Ingelfinger is pointing to an important concern but, from our experience, we are unconvinced about the sufficiency of his solution that the physician simply recommend a course of action.

If we were able to speak back into the medical system we would suggest that a more dialogical approach to decision making with regard to Bethany's care would have been helpful. Here the insights of Mikhail Bakhtin, the Russian literary theorist and philosopher, might prove helpful.\(^8\)

Bakhtin contrasts the dialogic with the monologic.\(^9\) The monologic is the one voice speaking in such a way that other voices are unacknowledged, unheard, or even subsumed. It would, for example, be the medical voice being heard, over and above the parental voice; or the parental voice, being heard over and above the medical voice. Embedded in monolosigm is the assumption that there is one

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8 For an attempt at bringing Bakhtin into conversation with physician-patient interaction see Hawkins (1993; 1996).
9 For Bakhtin's main works on “dialogism” see Bakhtin and Emerson (1984) and Bakhtin and Holquist (1981). For a comprehensive account of Bakhtin's understanding of the “dialogic” and “dialogism” see Holquist (1990).
true perspective which is privileged (Herrick 2012, 234). The dialogic is multiple voices in dialogue, not talking in parallel, but rather listening to each other, sharing ideas, creating a shared space whereby new thoughts, new creativity and new truth can emerge. With the dialogic, difference, rather than being a problem, is actually necessary (Holquist 1990, 20). Dialogue, by its nature, takes place in the space of difference. Real dialogue is therefore polyphonic, or multi-voiced.

It is in this kind of dialogue that "the other" is encountered without "otherness" being diminished. This is dialogical encounter. In contrast, monologue closes down the world, bringing a "discursive death" to the other who remains unheard, unrecognised and thus finds themselves in a state of non-being; the ultimate isolation (Robinson 2011).

For us, the medical system was not imposing its monological voice on us, for which we are grateful. But neither was it allowing any real dialogical encounter. It was as if two parallel voices (the medical voice and our parental voice) were exchanging words within the confines of particular roles and boundaries which had been set by the system.

Dialogism recognises the multiplicity of voices and perspectives. Obviously the medical staff brings a perspective that we, despite our best research efforts, cannot possibly have. With their voice they bring medical knowledge, experience and stories of similar cases. The voice of a parent will bring love for the child, emotion, hope and their own history. They may also, like us, bring their particular religious faith commitment.

Between our different voices a space was opened up; a potential space for dialogue, the dialogic space, or in the words of Martin Buber, "the space between". In talking about "real conversation" Buber states that, "what is essential does not take place in each of the participants or in a neutral world which includes the two and all other things; but it takes place between them in the most
precise sense, as it were in a dimension which is accessible only to them both" (Buber 1949, 241–242). For Buber it is the recognition of this space which creates the "I-Thou" relationship (1958). This is where real “encounter” happens. In practice, our experience was that we were left alone in that space. The medical staff spoke the words they were qualified to speak and then withdrew. A true “dialogical encounter” between ourselves and the medical staff would have reduced our feelings of being alone in a confusing and disorienting place.

We are aware of the ongoing debates within the medical literature with regard to the extent of authority given to the parental voice regarding determining the "best interests" of children (e.g. (Bahus and Føerde 2011; Wellesley and Jenkins 2009; Birchley 2010; Alessandri 2011; Cornfield and Kahn 2012). This debate feels like a battle between two competing voices: which one should have ascendancy and under what circumstances? Notwithstanding our "non-expert status" the medical paradigm seems to us more monological than dialogical.

For a more dialogical approach to be worked out in the practice of medicine, we suggest that medical staff be trained, both initially and on an ongoing basis through continuing education, in a more dialogical way of relating to patients. This would not just be a matter of skill-based competency, but exploring the philosophical basis for a dialogical encounter rather than a monological approach and discerning how this might work out in practice. In addition, there could also be a role for hospital chaplains, spiritual care staff, counsellors or social workers in potentially mediating dialogical encounters between patients and medical staff particularly in situations of life or death decision making, especially when the patient holds to a strong religious or moral perspective. Even their presence, and the addition of another voice with another perspective, may in fact open up a richer dialogical space, allowing patients like ourselves to not feel as isolated in the onerous task of decision making.
Conclusion

As Kingsley (1987) so creatively expresses in her *Welcome to Holland* essay, parents of handicapped children, anticipating arrival in Italy for the wonderful adventure of parenthood found themselves arriving in country they are simply not prepared for. They feel dislocated, confused and very often alone. This was our experience.

During Bethany’s pre- and post-natal life, and in the stressful days leading up to her death, many difficult and distressing decisions needed to be made, which we felt ill equipped to make on our own. While the pluralistic, and patient/parent centered, Canadian medical system gave us space for our faith to be respectfully factored into our decisions, that space also meant a sense of disorientation and aloneness. The system would not, or could not, engage with the particularities of our faith commitments. In our moments of deepest need the system pulled back, meaning that there was no-one to assist us, or partner with us, in the challenging work of our ethical decision making.

In this paper we have suggested a dialogical approach, based on the philosophy of Mikhail Bakhtin, could be useful for providing a model of parent-physician relationship particularly during the distressing times of making life and death decisions. Such an approach does not minimize the differences between the voices of the medical system and parents such as us with particular faith commitments. It is in the space of difference that collaborative solutions can arise. On the basis of our experience, this is one way in which the burden of stress created by being alone in a foreign system could be eased.

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