Partners in Care – case study

Spiritual Care at end of life for refugee communities

Context

The Partners in Care co-design programme was an opportunity for the Spiritual Care Advisory Group at MidCentral DHB (MDHB) to contribute to a hospital-wide approach to partnering. However, because we had no particular presenting issue before us, the group decided to focus on the issue our consumer representative presented. This made sense at the time but as we progressed it was clear that whilst end of life issues might be of concern to some people in the refugee community, there were other, perhaps more pressing issues that emerged.

Our greatest learning was to understand that an agenda decided by one group, even although it might be well intentioned and relevant, might not be what people want to talk about first, or at all.

Aim

To work in partnership to improve our understanding of refugee communities needs at end of life, so that the DHB can offer a seamless service from hospital to home, and in the process determine training needs.

Capture

After engaging with key staff in hospice and the hospital we were able to include an experienced hospice nurse in our team, along with our consumer representative, nurse director, psychologist and spiritual care coordinator.

Our community representative then helped identify the leaders in the refugee community who were then invited to a meeting as the hospital. Our initial challenges at that first meeting were getting people to attend and find the location, and for us to learn to work with an informal interpreter as we tried to explain the project.

The positive step from this meeting was the engagement and enthusiasm for the project from a Red Cross social worker, who became a key champion and communication link, as well as a facilitator of process with the refugee community.

Our second meeting was held at the Red Cross rooms with a second refugee group, none of whom had been at the first meeting. This time the whole meeting was run through a more experienced interpreter, which had the interesting impact of slowing things down, enabling more reflection about what was said and an ability to return to issues that were left unfinished.

The positives from this meeting were in building more relationships and finding a topic that would engage this community further, that is, Muslim prayer space at Palmerston North Hospital, even although it wasn't our anticipated issue of engagement. The second achievement was for people to feel comfortable enough in that meeting to begin to share some of their own personal experiences and to help us link with a young Afghani woman who was prepared to be interviewed.

This led to two meetings with a young Afghani woman (called 'S' for the purposes of this case study), her support person and an interpreter. When she came to hospital, S *was 'a bit happy, more frightened, didn't know the language, the system is different and had no family.'* In Afghanistan or Pakistan, a person would have family with them in hospital.

S stayed in hospital for eight days. As a result of the conversations we identified two significant themes:

Food

'The food was very bad, no taste. No salt, no oil, no tomato, no onion. In the beginning what they would bring me, I didn't like it and stuck to salad. When the menu came to choose I didn't like the food. A nice lady would ask every day why aren't you eating and I said I didn't like it. Friends brought food in.'

Some food was labelled 'halal' but when S asked about it, she realised that this was not correct as the halal food was cooked in the same pot as the non-halal food.

She said it was *'very difficult one day, no salad, so hungry! I was crying and nurses found a salad somewhere…Not well enough to leave after seven days but so hungry, crying wanting to go home.'* S thought some staff might have noticed and realised she was not liking the food.

Did anyone ask you for feedback on your experience?
'No.'

Language

S didn't have an interpreter for much of the time in hospital but she was *'able to talk some English.'* And*, 'staff were really, really good, listened a lot, tried to comfort me. Some staff knew some Urdu.'* Telephone interpreters were not used. Although there was a note for staff to contact a friend who could interpret, this was not usually done, but he did interpret before her operation. On one occasion when S was feeling sick a gentleman from the Afghan community was called in to help.

Was there an interpreter when doctors visited?
'No.'

How did you know what was happening?
Doctors *'only came once or twice, pieces of paper, would ask questions, tell me things.'*

Tools

Our tools were:

1. Being prepared to work with a third party (Red Cross social worker) to help facilitate the process.
2. A willingness to listen and then reflect on our initial expectations and assumptions as they were challenged.
3. Engagement in open conversation that took us to places we hadn't anticipated.
4. Note-taking that was then fed back to the participants to check accuracy.
5. Learning to work with interpreters who taught us much about being still.
6. Being prepared to trust the process rather than try to control it, and in so doing, remain open to an ongoing relationship.

Understanding

Overall, we were pleased with the formal conversations we engaged in and the informal interactions that went on just so that we could gather people together and keep the process moving. However, we recognise that all of these conversations were just opening moves in relationship building and in beginning to understand what is important to the diverse community that we serve.

Trust mattered in all these interactions as it does in any relationship. Although people wanted to tell us how grateful they were for the kindness and care of staff who had listened and comforted them, it was only as they started to get the measure of us that we got onto some aspects of experience that have been far from ideal.

Improve

We have been grateful and humbled by the generosity and thoughtful feedback from the refugee community and also acknowledge the need for us to be changed by these encounters and respectfully offer the following suggestions for improvement.

Relationship building

As we reflect on our engagement, we've come to understand that we behaved in a way that fostered relationship building rather than offered a pre-packaged service. Whilst this may take longer than an organisation defined project with clearly defined outcomes, we suggest that MDHB look at the potential for appointing relationship facilitators as a positive way to build trust and further partnering with people, families and whānau.

Time frames

We all live with the 'no time' virus and this can blur the ability to truly see one another, as organisations seek to achieve what they want in a stated time frame. However, communities have differing priorities to those of a health system. Trying to impose our timeframe muddies the water and limits the ability to converse openly and properly work in partnership. We suggest approaches that are focused on long term relationships rather than temporary projects if MDHB is to partner with integrity.

Communication

Language clearly matters for all of us and whilst there nothing better than professional interpreters, we recognise there are some functional realities in hospital. However, S showed us how comforting it was for her to just hear words in a language she could understand.

Like Emirates Airlines, we suggest that MDHB become proud of the various language speakers on our staff, compile a register that is rigorously kept up to date, ensure staff wear the language badges they can speak and enable them to offer interpreting services whilst they are on shift. This can make all the difference. In addition, there are now easy to use language apps like Google Translate that can help us understand one another and ensure our faces light up.

Alongside this is the need to be alert to modesty issues and to be open to requests for a doctor of the same gender as the patient, unless in an acute situation when the patient's health care will take priority.

Food

Food is one of the major vehicles of love and compassion in any culture and a symbol of commitment in a number of religions. This means it is important in the daily lives of all human beings for much more than just its health benefits.

For S, the food choices we had on offer were tasteless and unpalatable, even though we might think they were healthy and sustaining. Added to that was the absence of certified halal food, which meant S had a very restricted food choice to the point where she experienced hunger and distress. Even so, she was gracious and understanding, continuing to express her appreciation for the care she had received.

To assume that what we believe about food and its preparation is right in everyone's eyes is to override a significant element in the way other people make meaning.

We suggest that MDHB consider reviewing its food choices and preparation styles based on feedback from consumers, making sure that people from a range of cultural and religious traditions are heard in this process.

Spiritual space

As many New Zealanders have moved away from connection to formal religious traditions, there has been less emphasis placed on the need for or accommodation of religious rituals. We now need to re-engage to understand the importance of these for the health of people at an individual and community level.

Our Muslim neighbours are helping us with this by pointing out their obligation to pray at appointed times throughout the day and the complications of that in the ward setting, along with the long distance required to get to the existing chapel. Even so, they were appreciative of staff that were accommodating of these needs. There was keen interest in being part of a discussion about how we develop the chapel into a sacred space that reflects a wide range of religious and cultural traditions.

Finally

As our small project group (Barry, Dianne, Indra, Lizzy and Sande) began to evolve, we were better able to focus on what people wanted to give us feedback about. Whilst our project was formed around what mattered to people at end of life, and although that was important to the groups we met with, it was only one aspect of what people were concerned about as they shared their health and hospital experiences.

We were also intent on hearing individual stories as set out in the Partners in Care guidelines. However, we had to realise that building relationships is the first step and the most important priority. If that happens and happens well, the stories will emerge in their own good time, particularly if they are fostered along by relationship facilitators.

Although we did not reach the goal set at the beginning of our project, we are confident that the relationship work we have begun will continue as all projects are now part of MDHB Spiritual Care Advisory Group's workplan.

And in the end, our experience shows that if we are going to truly partner with people, we have to be open to being changed by that engagement. Without that we will remain in control.

Names, email addresses, organisation and DHB of team members

Name	Role	E-mail address	Organisation or DHB
Indra Dulal	Consumer		
Barry Keane	Health sector		
Dianne Boon	Health sector		
Lizzy Kent	Health sector		
Sande Ramage	Health sector		