



A *rafoogar* at work (Photo credit: Priya Ravish Mehra)

Recently, I delivered the Second Hinohara Lecture at the Asia Pacific Hospice Conference held in Penang, Malaysia, and likened the work we do in palliative care to that of the *rafoogars*. I suspect I confused a number of people with this reference. In an effort to rectify this, below is a short note.

### CanSupport: Mending Bodies; Healing Lives

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The *rafoogars* are a community that currently resides in several villages in northern India. They have for centuries been repairing damaged textiles and preserving rare and treasured items like Pashmina shawls. Their skill lies in their ability to use techniques that make their mending invisible to the naked eye. A skill which it is believed their ancestors brought with them from Central Asia. Unlike other craftspeople, however, they have remained uncelebrated over the ages and even today are marginalized people.

In my Hinohara lecture delivered at the recently concluded APHN Conference held in Penang, Malaysia on the 16<sup>th</sup> of July, I expressed a sense of kinship with these *rafoogars*. A kinship born of the fact that at CanSupport we too help people traumatized by the news that they have an incurable illness or a life limiting condition to continue to hope for a life free of pain and suffering. These are people who have a tear that extends to the very centre of their being where medicines and machines cannot reach. This inner tear can only be repaired by a master craftsman and his/her team. This is when people turn to the palliative care team in the hope that their experienced and skilled hands will still be able to wield the needle and the thread in a manner that will mend the tear while ensuring the continuing integrity of the entire garment.

This is not a job that can be accomplished by the faint hearted nor is it possible for one person to do it alone. It requires courage, wisdom, self awareness, training, experience and good team work. It also requires full knowledge of the garment to be mended: how it feels to the touch, what kind of a weave it has, etc. This is generally done by listening patiently to the patient, responding when required and in an empathetic way and by observing existing relationships within the family. It also requires identifying the most important and pressing needs of the patient and prioritizing them. These can include the need for pain and symptom control, good nursing care, counseling, economic assistance or spiritual support. Once this is done, these teased out threads can be woven into the weave of the existing fabric with the support of the patient and the family to mend the tear.

The skill of the rafoogar lies not only in making the part of the garment that has been darned invisible to the outside eye but also to the inner eye of the wearer. After all the wearer must not feel that he or she is wearing a damaged and therefore unworthy garment. Accordingly, it now becomes the task of the palliative care team after weaving together threads to cover the tear to make it disappear so that the repaired garment can again be worn with pride. This is a healing moment when the eye no longer seeks the mended tear but instead focuses on the larger untouched garment and revels in its beauty.

The patient is encouraged to let go of past grievances, to forgive and seek forgiveness, to express and receive love freely and to say final goodbyes. The rafoogar too must similarly be ready to feel deeply and then let go as he moves on to the next precious garment offered to him for mending.

There is a growing clamour to get the rafoogars recognized as craftspeople whose skills are needed to repair and restore antique and precious garments, shawls, carpets, etc., that are falling into disrepair. The APHN Conference echoed this theme when it called for palliative care to be integrated into mainstream medicine. The challenge that chokes the art of the rafoogar is that we live today in a world where that which is damaged is not to be repaired but thrown away. Already there are calls that the answer to a debilitating and life limiting condition is not palliative care but euthanasia. Is our survival dependent on the survival of the rafoogar?