

The birth...

Kosish was born out of a 'sankalp'...a promise, a determination to create something, born out of a necessity, an urgency, which began as realisation dawned upon me during my arduous hours in a critical care unit(CCU) back in 2000. Watching patients die lonely, painful & undignified deaths, hooked on to ventilators & other life supporting equipment, their hands tied down by restraints, their desperate gaze seeking out a familiar face amidst the masked & foreign faces of health care personnel; hunting for a wife, son, daughter, grandchild, while they wait hardly 40 feet away behind the walls, away from sight, for they are not allowed in... And as the 'prana'(soul) leaves the sthula sarira (gross body), one leaves the mortal body steeped in regret...if only things could have been different...

That was when my sankalp was born, to ensure that death should be dignified & pain free, not only physically but also psychologically, socially & spiritually. For death is the only event in our existence that comes with a guarantee. But sadly, in all the other events in our life, which come with 'if's' & 'buts', we invest our time, energy & money! But none for the only guaranteed event in our existence...our death. So, I undertook my sankalp to invest my time, energy & money to help ensure that the process of dying could be made more dignified & meaningful. I was not exactly born into a rich family & had to struggle very hard to complete my education. I took out a loan from my provident fund to purchase a plot of land, where I envisaged myself spending my last days of life...My family stood beside me like a rock & so did a colleague of mine, putting in her savings as well.

Our Kosish was born.

What made Kosish unique that it was located in a rural setting, amidst nature, with a rivulet flowing by the centre. In order to better understand the needs of the "Indian", as far as palliative care was concerned, I undertook a long journey covering 8 states of India, driving a car, sleeping in 'dhabas', interacting with the 'common man' (I had no access to funding & what was planned as a trip all over India had to be curtailed to just 8 states). Poverty, I then realised, was a larger unattended need, overshadowing palliative care.

It was then that we started addressing poverty as well...

We started a unique programme in which we encouraged the little children of the surrounding villages to come to our center, where they were given 'value education' & most importantly, a healthy meal. We focussed primarily on the 'girl child'. What started off with 5-8 children rapidly increased to around 70 children & once more we were struggling to feed them, for we had no access to funding. But then the almighty smiled down upon us & help started coming from angels...for every donor was an angel!

We organised health check-up camps for the Elderly in remote villages in Jharkhand & adjoining West Bengal, diagnosis & treating causes of mortality & morbidity like hypertension, osteoarthritis, depression, malnutrition & loneliness... We partnered with Clothes Box Foundation who supplied us with clothing, which we freely distributed among the Elderly & children. A unique 'home-care' programme for the rural Elderly was started in which empowered ladies from villages would conduct door-to-door surveys of the Elderly, talk to them enquiring into their well-being, check their BP,

administer calcium & vitamin supplements & even supply blankets to them in winter. We have recently upgraded this programme to include distribution of food (sattu, gud, chura) for the Elderly.

Home-visits for the terminally ill cancer patients has been something that we had been doing since 2005. It did not matter if the patient stayed 100km away, for we believed in 'quality' rather than quantity. Home, we believe, is the best place to die, for the terminally ill..."where would you like to die?"

Home-care is the 'backbone' of palliative care & if you are not doing home-care, you are simply not doing palliative care.

Period.

Addressing spiritual & existential concerns, I realised, was of paramount importance in treating terminal pain. 'Meaning making' became important as the dying desperately tried to make a sense of meaning out of their suffering. The desperate, searching gazes of the dying in the CCU had been my prime motivation to embrace palliative care & I used empathy & compassion as a tool to address these issues. Religion & ritualism, things that I used to scoff at, suddenly made 'sense' to me & I delved into study of religion to help my patients in meaning making.

Interacting with the dying, I familiarised myself with the art of helping the dying in 'letting go', guiding them through the mysterious doors of after-life, like the little tugs which help guide the ships through the busy & congested harbour, out into the vast ocean...

Focussing on Holism...

I imagined myself bedridden, helpless, anxious, in pain...& what I would want in those circumstances...what would be my needs?

Right from a safe, familiar environment to preservation of my comfort & dignity, including relief of pain, I felt, that my list was not very much & pretty much attainable.

And thus, I incorporated those 'needs' into the training programme for the Nursing Aides.

Right from a compassionate presence to preparing my favourite bowl of soup & serving it in an aesthetically pleasing manner to a relaxing foot massage, I would want it all, in addition to fine nursing skills.

And it comes as no wonder when David Tasma, a patient of Dame Cicely Saunders, had commented, "I want what is in your head & in your heart"!

Meaning that a dying person just does not seek comfort from a physical aspect only, but seeks comfort of his soul.

So we taught them how to lay a table in a manner that would be pleasing to the eye & create that warm bowl of soup which would infuse warmth into a cold body...

We agree that we cannot cure always...but comfort, yes, that is something that we can definitely provide for!

For the aim is to 'heal'... the body, the mind & the spirit.

As as we visited the 21 year old with cerebral palsy with spasticity, the 'basic needs' of man were reaffirmed...food, shelter & mate.

Looking from the perspective of a dying man, it translates into comfort food, a familiar environment like home(the best place to die) & the presence of a familiar person who would look after your needs.

Hence, we train our Nursing Aides thus!

So what will be your needs in your last days of life...

I was actually caught unawares...this being a virgin venture in India, there was no precedence to learn from. And to top it, I hardly had any access to funding. Limited funding roughly translates into limited availability of resources which very often forces you to 'cut corners'...but then that was where I made no compromise. The result – I had to dish out money from my personal savings.

I have been pioneering the cause of palliative care in rural Jharkhand & adjoining parts of West Bengal since 2005. Working in resource poor settings prompted me to reflect back & contemplate on possible solutions to address the challenges that rural palliation posed in a country like ours, where palliative care is still a developing speciality & lacking a National Policy. The challenge was to help reach palliative care to the grassroots levels. The existing ANMs (auxillary nurse midwives) were already burdened with the tasks of ensuring vaccinations, safe motherhood practises, etc & burdening them with an additional task of providing palliation seemed unwise. For palliation is all about 'quality' rather than 'quantity'. Also, visualising the potential of utilising the skills of the village women, given the advantage of their local cultural & social familiarity, resulting in their 'acceptability' by the local community as well, I envisaged upon a programme to provide 'home-based care' for the rural Elderly, which would address their concerns on a 'holistic' level. The interested ladies were given a short period of training in our rural Hospice, Kosish, after which they began a door-to-door survey of the rural Elderly in each village. The concerns of the rural Elderly were enquired & duly addressed with the result that not only did the programme become popular in the concerned villages, but also elevated the stature of the rural ladies in the villages. The Elderly would now look forward to their visits eagerly, for now they had access to a compassionate ear & a healing hand. This service was further upgraded to include delivery of medications to treating hypertension, aches & pains, vitamin & calcium supplementation, distribution of clothing & blankets & even distribution of nutrition. We focussed on 'sattu', which is locally available, accessible, acceptable, easy to store for prolonged periods & ease of preparation by the Elderly, this not requiring further cooking. Also, this was a 'balanced' diet, providing proteins, carbohydrates & even fat when mustard oil was added to it, as relished by the local community. Lack of a steady source of funding forced us to scale down the extent of coverage over time, but the operations are still on.

It was then that I decided to venture a step further to create the 'Palliative nursing Aide' programme.

A total of 10 students were enrolled in the first batch. 9 village women & one male, who is an auto-rickshaw driver as well & demonstrated a sincere eagerness to join the programme. The course fee was capped at INR 10,000 for a period of 6 months, which they could barely afford. It was then

Madeline Kerkhoff from Kicozo, an organisation specialising in aromatherapy, volunteered to offer scholarships of 50% for the entire batch. But then the girls requested for staying 'full-time' in-campus, something that we were not prepared for. They were also not in a financial condition to pay-up for their food. We were now faced with an additional challenge of having to provide for 3 meals per day for 10 inmates, meaning 30 meals per day! Roughly calculated, keeping things on the leaner side, this worked out to be an expense of nearly INR 3000/head/month, meaning an expense of INR 18,000 per student over 6 months. Even after their scholarship, they were actually just paying INR 5000 per student over 6 months! Coupled with the costs of fuel, maintenance, additional staffing, we were actually faced with the prospect of dishing out something like INR 1.5 lakhs over 6 months! I started to dig deeper & deeper into my personal savings...

All the enrolled girls were 'officially' class XII pass (with one exception), but their actual level of literacy & cognition was pathetically poor. It was like teaching a 10 year old child. A long journey had begun. I stuck on doggedly, along with my team & support from my wife...little steps, little joys of teaching & learning, driving daily for around 55km for months on the end...

We realised that the needs of a potential 'client' from a city might be different...so we actually created the 'Bulbul finishing school for rural women', where we taught them basic table manners, ways to serve & conduct themselves in a modern household. In order to promote 'holistic care', special emphasis was given on the art of 'listening' & other non-pharmacological modalities of therapy, of which the Siddha technique of Varmam massage was judiciously used to ensure comfort. They were also taught how to prepare simple & nourishing meals for the bedridden patient, including feeding them with patience. Special emphasis was given to respect & maintain the dignity of clients.

After-life, I realised, was something that was plausible...for it has its roots in 'hope'.

The journey continues...

We have now started the second batch with 14 students.

www.kosishngo.org

Kosish is a registered NGO in India.