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Editorial

When Christ was accused of spending His time with sinners, He gently rebuked his accusers with the question who needs a doctor, the healthy or the sick. As the year comes to an end and we take stock of our frailties and many moments of physical and spiritual weakness, we have a reason to be joyous: a smiling and cherubic babe in manger, a babe who is a magnificent manifestation of God's infinite and unchanging love for us; a babe whose sole purpose is to heal and comfort us.

The singer Russ Lee sang "I smile when I think about the way you turned my life around, I smile about the happiness in you I found." May we all smile as we contemplate the birth of Christ. May this Christmas and the following year be filled with the joy of Christ.

- Sr. Lalitha Teresa
Editor



The Nature of Holistic Care

1. Thinking about Holism

In the UK, help the hospices has stated that palliative care should practice the principles of holism. So what is holism? One might usefully begin to answer this question by looking in a dictionary. The Oxford English Reference dictionary offers two definitions under the entry for holism, and both help us to think about holism. The first definition is described as coming from philosophy and states, 'the theory that certain wholes are greater than the sum of their parts. The second definition is labeled as from medicine, and states 'treatment of the whole person including mental and social factors rather than just the symptoms of the disease.'

Thus we are reminded in the first definition that people are more than simply collections of atoms and molecules – people have a dynamic and dimension to them that is not acknowledged if we treat them as purely bio – chemically functioning organisms. The second definition implies the same idea by saying that we must treat the whole person, and not deal with patients as simply a diseased body. Sheldon (1997:9) reminds us that this is a demanding task;

'A holistic approach involves valuing all the characteristics and past experience of this person, not just seeing them in terms of their diagnosis or presenting problem.'

The WHO (1990) definition of palliative care implicitly calls for a very thorough going holism. It describes palliative care as:

The active total care of patients whose disease is not responsive to curative treatment Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.'

This definition tells us that in palliative care we must address four dimensions of the person – their physical being, psychological being, social being and spiritual being. And do not miss the presence of the word ‘paramount’ in the definition. Here we are being challenged to care for the whole person – all the elements of their being. You can see parallels between the WHO definition and what we discovered in the dictionary.

Thus the aim of palliative care is to promote the well being of patients in order to enhance their quality of life (Cobb 2001). This means trying to minimize those things that undermine their wellbeing and to maximize those things that advance their wellbeing. To do that demands an in-depth knowledge of the patient and the things that worry them and give them pleasure. This is an agenda that clearly exceeds just attending to their diseased body and involves their whole person – we might say it necessitates dealing with their spirituality.

2. Holistic Care

Having thought about the word holism, we must not ignore the word ‘care’ There is a lengthy entry in the dictionary under the word care. Some of the words and phrases noted there are:

- to be troubled or concerned; to be affected emotionally Ö
- to have regard, affection or consideration for Ö
- to provide physical needs, help or comfort Ö

In palliative care we give full value to caring. We care about Patients and for them – in line with these ideas from the dictionary. We can also see that care is always expressed in a relationship between people. And in a real relationship both parties are equally important. A health care relationship can easily fall into an unequal relationship, for after all, one of the parties is sick and needy, so it is easy to see how paternalism creeps in. Good carers share their advantage, acknowledging need and promoting growth in the other. They are not deliverers of care, but co – operators, companions, co – responsible for the care. Campbell (1984) nicely reminds us what a companion is:

‘Ö the good companion is someone who shares freely, but does not impose, allowing others to make their journey.’

Thus we see that we can only enter into a caring relationship when the other person is fully acknowledged. Further more, a caring relationship can only be maintained if we place importance upon listening. Unless we hear what the other person needs, we cannot fulfill those needs. It should therefore be clear to you that caring is a moral

ideal rather than task – oriented behaviour (Magee 2000). Professional care is a form of loving that cannot be captured solely in the language of contract – it goes beyond that. The end result of good care is healing – though not necessarily curing (discussed below).

Henri Nouwen, a French theologian writes strikingly about the meaning of care

‘Real care is not ambiguous. Real care excludes indifference and is the opposite of apathy. The word “care” finds its roots in the Gothic “Kara” which means lament. The basic meaning of care is: to grieve, to experience sorrow, to cry out with. I am very much struck by this background of the word care because we tend to look at caring as an attitude of the strong towards the weak, of the powerful towards the powerless, of the have’s towards the have – not’s . And, in fact, we feel quite uncomfortable with an invitation to enter into someone’s pain before doing something about it.

Ö When we honestly ask ourselves which persons in our lives mean the most to us we find it is those who instead of giving much advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is the friend that cures.’ Nouwen 1974, p33-34

The eminent nurse theorist Jean Watson suggested the following factors as important elements in good care of patients

We care by

1. Giving assistance to gratify human needs;
2. Developing a helping / trusting relationship;
3. Bringing a ‘Scientific ‘ problem – solving system of organization into our decision – making;
4. Providing a supportive, protective environment;
5. Instilling realistic hope and faith;
6. Teaching our clients to cope;
7. By giving and extending our sense of self;
8. Through promoting acceptance of both positive and negative feelings; (Because intellectual and emotional understandings of a situation may differ)
9. By cultivating sensitivity to the impact of culture upon self and others;

10. By helping patients to see that perceptions of reality are sometimes flexible – it's not what happens, it's what you make of it.

Holistic care endeavors to engender in the patient/ client a greater sense of harmony and well being in terms of their mind, body and soul. Central to care is a relationship between the carer and the cared about in which the carer uses their knowledge and skills, compassion and concern for the other with respect and in accordance with their needs and wishes. Those who care are particularly concerned to help clients / patients who suffer. We cannot cure another person's suffering, but we can be with them in their suffering and help them to face it and find meaning in it – we do not leave them to feel alone at such impossibly difficult times. Care is directed by:

- ★ Patient and family values;
- ★ Extending dignity and respect to patients and families;
- ★ Telling them the truth – insofar as they invite us to share it;
- ★ Offering them good information so that they can make informed decisions and act autonomously.

3. Actions to Generate Holistic Care

- ★ Listen to the patient
- ★ Be aware of the wider life context within which the patient's health problem is set
- ★ Encourage the patient to tell you their story:
 - their version of events
 - their assessment of 'things'
 - their perception of the future (how they read the road ahead)
- ★ Try not to limit the expression of spontaneous emotion
- ★ Provide the patient with a secure base from which he/she may explore their circumstances
- ★ Keep reflecting back and trying to connect information with the patient
- ★ Link past, present and future with explanation in clear, simple language, avoiding medical jargon.
- ★ Where possible, offer the patient alternative explanations for consideration (to the ones they have thought of)
- ★ Don't tell the patient what he/ she is feeling – ask them
- ★ Don't ever devalue physical symptoms or encourage patients to "put up with it".
- ★ Ask for honest feedback from patients
- ★ Help the patient to explore the role he/ she may have in bringing about events/ situations

- ★ Draw the patient's attention to the way in which he/ she conducts their relationship with you
- ★ Be clear about your own feelings and where they are coming from – do not contaminate this encounter with past ones
- ★ Keep questioning yourself and checking – out your motives, instincts, feelings and reactions
- ★ Be open to the prospect of getting it wrong
- ★ Don't confuse distress with stupidity
- ★ Don't assume that as a nurse/paramedical worker you are in some way superior to the patient or less vulnerable
- ★ Don't assume that what is unacceptable to you is necessarily acceptable to the patient
- ★ Get supervision and look to your own wellbeing in this difficult work

4. Healing

Cure is not the only acceptable outcome of medical treatments. Moreover, if one thinks about the concept of care, i.e. Palliative care rather than palliative medicine, one catches a glimpse of an holistic concern for the person that reawakens interest in the possibilities contained in the concept "healing." Cure is concerned with the eradication of disease, the end of the disease process through medical intervention. Healing, on the other hand, has a wider connotation, a journeying towards wholeness of mind, body and spirit; the gaining of an inner peace even if one does not like what is happening (Stoter 1995). Kearney (2000) says he thinks of healing as 'the process of becoming psychologically and spiritually more whole; a phenomenon which enables person to become more completely themselves and more fully alive.'

It is possible to experience deep levels of healing and wholeness without being cured. The converse is also true: that people can be cured of disease without achieving much in respect of the process of healing and wholeness.

Cohen and Mount (1992) Wrote

'Palliative care involves the skills of the mind embodied in competent medical care, but also demands the friendship of the heart with its caring, acceptance, vulnerability and reciprocity. Neither alone is sufficient.'

This demand means that you must also take care of yourself – know how to recharge your batteries. But if the care relationship is good and reciprocal, that is if you allow your patients to care about you too, hopefully you will find your reservoirs of compassion being refilled. Marie de Hennezel (1997:130) said that love, far from being a reservoir that begins to drain with use, refills the more it overflows.

One Day Workshop in Palliative care for Nurses – A Report

Jeevodaya Institute of Palliative Care conducted the first Workshop for Nurses after up-gradation as a Regional Training Centre by IAPC on the 15th of November 16, 2008 at Jeevodaya, Chennai.



The participants were the student nurses [20 students and one faculty member] doing their 1st year of their Masters in Nursing [MSc –Nursing] at Vel RS Nursing college, Avadi, Chennai.

The programme started at 9am – Registration followed by a Welcome address by Sr. Lalitha Teresa.

The principles of Palliative Care were beautifully explained by Dr. Pacifica Simon – Retired Professor of ENT from Madras Medical College who has been associated with Jeevodaya as an Honorary Medical Officer for the past 10years.

Dr. Manjula Krishnaswamy, Honorary Medical Director of Jeevodaya emphasized the need for including ‘Pain’ as the ‘Fifth Vital Sign’ in routine assessment of a patient by a nurse, while explaining the need, the methods for accurate assessment and management of pain with particular stress on the nurse’s role. They were introduced to the WHO analgesic ladder and the concept of ‘Total Pain’. They were also taught briefly about management of other common symptoms such as Nausea and Vomiting and Dyspnoea.

After lunch, the participants were taken on a tour of Jeevodaya where they interacted with the patients. Sr. Deena, the Nursing Superintendent, explained to them the nursing practices in Palliative Care highlighting the

inno-vative and cost-effective measures adopted by Jeevodaya – such as bandage making from old cotton sarees, using raw papaya for bed-sores, and ginger grass oil for masking malodour. The participants acknowledged that they were hearing about these practices for the first time. Sr. Lalitha Teresa’s exposition of the importance of developing communication skills especially while dealing with patients in the palliative care set up was received with awe and applause as it was drawn out of a rich experience of working with hospice patients for the past 18 years.

For both the faculty and the participants the day’s programme was very gratifying as most of the nurses had had good work experience [2 to 8 yrs] after their graduation and so were able to interact very meaningfully.

The day ended with the nurses receiving their certificates of participation from Sr. Liberata, Executive Director of Jeevodaya. Many of the nurses expressed a wish to enroll for the next IAPC Certificate Course in Palliative Care.

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