An Indian Primer of Palliative Care

For medical students and doctors

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7. PALLIATIVE CARE FOR THE VULNERABLE AGE GROUPS

Palliative Care for Children

Everyone loves children, but often we do not consider them individuals; often they are considered almost inanimate beings and their feelings are ignored. They too have rights to be considered as individuals and to be treated with respect, not just affection.

The World Health Organization defines "palliative care for children" as[45]:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

45 World Health Organization. WHO Definition of Palliative Care for Children. Available at http://www.who.int/ cancer/palliative/definition/en/

Depending on their age, there can be considerable differences in their thought processes. Though generalizations are always liable to error in individuals, the following developmental stages may be good for general guidance.

In children younger than 2 years of age, it is particularly important to provide physical comfort through symptom control and by avoiding procedure-related pain. Their comfort can be enhanced by assured presence of a parent even during intensive care unit (ICU) admissions or during procedures. ICU experience with parental separation may even cause post-traumatic stress disorder similar to victims of torture.

Children in the age group of 2-6 years may not understand the finality of death. They may see disease or death as punishment for their own mistakes or sins. They need explanations and reassurance and continuous parental presence to endure the experience of a chronic disease.

Children in the age group of 6-12 years may fear abandonment. Avoiding parental separation is again an important consideration in planning tests and procedures. Communication is best done in a succinct manner. Older children have developed the ability to hear, evaluate and analyse information. For this reason, older children might be best served by facilitating their participation in decision-making.

Religious faith of children tends to be absolute, and prayers can be a source of comfort. This can also create grave problems, such as a sense of guilt that "it all happened because I was a bad boy" or "I did not pray hard enough!" Absolute faith also gives rise to fear of celestial punishment, even for minimal infractions.

Teenagers are often already struggling between the need for independence and the need for love and attention. While facing a progressive disease, their typical sense of indestructibility gets challenged by loss at different levels – physical capacities, roles, access to peers, opportunity to dream, sexuality etc. They may go through extremes of emotion, and will require empathetic non-judgmental listening and counseling.

Children as a family member of a sick person

There are usually major changes in the family dynamics when a family member is diagnosed with a serious illness or is undergoing multiple hospital admissions. The family's reserves are strained and the child may find himself/herself under the care of relatives or other strangers. Their familiar world collapses and he/she may see the disease as punishment for mistakes. They may irrationally worry about their own death or death of a surviving parent.

Children desperately need explanations regarding the illness and the changes in their lives.

Siblings of the children with disease are particularly at risk of neglect, because all the parents' attention may be focused on the ill child. It is important to recognize and discuss this with the parents. The parents' verbal and physical affection to the siblings are essential therapeutic tools to reassure the child of his/her important role in the family. Requesting them to help with care for the ill child might help them feel included in the family and may add to their emotional health in some settings.

WHO RECOMMENDATION FOR PAIN RELIEF IN CHILDREN

WHO uses the term "persisting pain" to address long-term pain related to medical illness, including pain associated with major infections (e.g. HIV), cancer, chronic neuropathic pain (e.g. following amputation), and episodic pain as in sickle cell crisis.

Behavioural indicators of acute pain in children are seen by observing facial expression, body movement and body posture, inability to be consoled, crying and groaning.

When pain continues unabated, these normal indicators might disappear.

Behavioural indicators of persisting pain in children
▪ abnormal posturing ▪ fear of being moved ▪ lack of facial expression ▪ lack of interest in surroundings ▪ undue quietness ▪ increased irritability ▪ low mood ▪ sleep disruption ▪ anger ▪ changes in appetite ▪ poor school performance ▪ fear of strangers

Undernourished children may not express pain through facial expressions and crying, but may whimper or faintly moan instead. They might have limited physical responses because of underdevelopment and apathy.

Assessment Tools

Caregivers are often the primary source of information, especially for preverbal children, as caregivers know the child's previous pain experiences and behaviour related to pain. The caregivers' behaviour, beliefs and perceptions can have a significant impact on the child's response to pain. The approaches used by parents and caregivers to console the child, such as rocking, touch and verbal reassurance must be considered when observing distressed behaviour.

Goals of care:

- **Relief of suffering**
- **Improvement in quality of life**
- **Strengthening the experience of childhood**

There are special vulnerabilities faced by children needing with serious illness. The child is often too small, too sick and too disempowered to ask for palliative care; the parents are often exhausted from the care of a chronically ill child and their other family commitments. The parents may also be unable to come to acceptance of incurability, and may therefore demand curative attempts even when futile, thus adding to the child's suffering.

Medications

WHO recommends that all moderate and severe pain in children should always be addressed. Inability to establish an underlying cause should not be a reason to conclude that the pain is not real.

Depending on the situation, the treatment of moderate to severe pain may include non-pharmacological methods, treatment with non-opioid analgesics[46] and treatment with opioid analgesics.

The benefits of using an effective strong opioid analgesic (morphine) outweigh the benefits of intermediate potency opioids (tramadol, codeine) in the paediatric population. The risks associated with strong opioids are acceptable when compared with the uncertainty associated with the response to codeine and tramadol in children.

It is important to select routes of administration that may easily be used in children e.g. liquid formulations. Intramuscular route is painful and is best avoided. Rectal route also may not be suitable due to unreliable bioavailability, but may be considered based on the setting.

Medicine	Neonates 0-29 days	Infants 30 days -3 months	Infants and children 3 months to 12 years	Maximum Dose
Paracetamol	5-10 mg/ kg every 6-8 hours*	10 mg/ kg every 4-6 hours*	10–15 mg/kg every 4–6 hours* #	Limited to: 12mg/kg every 6 hours, if for longer than 4 doses/day.
Ibuprofen	(Not Recommended)		5–10 mg/kg every 6–8 hours	Child: 40 mg/ kg/day
*- Children who are malnourished are more likely to be susceptible to toxicity at standard dose regimens due to reduced natural detoxifying glutathione enzyme. # - do not exceed > 1 gm per dose at a time. **Morphine is the recommended 1st line opioid.**				

[46] World Health Organization. WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. Available at http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf

Breakthrough pain is characterized as a temporary increase in the severity of pain over and above the pre-existing baseline pain level. For example, if a child is taking pain medicines and has good pain control with a stable analgesic regimen and suddenly develops acute exacerbation of pain, this is considered breakthrough pain. It is usually of sudden onset, severe, and of short duration. A number of episodes of breakthrough pain can occur each day. It is a well-known feature in cancer pain but it is also seen in non-malignant pain conditions. Breakthrough pain can occur unexpectedly and independently of any stimulus, i.e. without a preceding incident or an obvious precipitating factor.

Incident pain or pain due to movement has an identifiable cause. The pain can be induced by simple movements, such as walking, or by physical movements that exacerbate pain, such as weight bearing, coughing or urination. Diagnostic or therapeutic procedures can also cause incident pain.

End of dose pain results when the blood level of the medicine falls below the minimum effective analgesic level towards the end of dosing interval.

Further learning:

A free e-learning program on palliative care in children is available with the International Children's Palliative Care Network (ICPCN) - http://www.icpcn. org/icpcns-new-elearning-programme/

Palliative Care for the Elderly

'National Policy on Older Persons' [January, 1999] by Government of India, defines 'senior citizen' or 'elderly' as a person who is of age 60 years or above. In India, the elders (7.4% in 2001) will account for 12.17 percent of overall population by 2026, which reflects the low birth rates and the long life expectancies achieved over the years. Being a vast country, India may face several problems with majority of seniors being illiterate and far poorer than their counterparts in the developed countries.

There is relatively higher ratio of females to males in the elderly population than in the general population since independence. The problems faced by the elderly women are exacerbated by their low literacy rate, customary ownership of property by men and lack of employment. About 70% of elderly women are totally dependent on others as compared to 30% of elderly men. Migration of youth to regions offering employment contributes to social isolation and helplessness of elders. It is not uncommon to see an 84 year old accompanied by an 81 year wife as the main carer.

Evaluation

Detailed history, examination and early specific laboratory and radiologic tests will help diagnostically to evaluate the elderly patient with a change in the clinical status. Clinical presentations for the elderly patient are often different than in younger patients, such as a sudden issue with intelligence, instability, incontinence, immobility – also known as the "Big Four" in geriatric care. Each of these symptoms should be investigated for reversible causes and not assumed to be a part of normal aging.

Investigations

Investigation is an essential tool in the diagnosis of elderly patients and best done early.

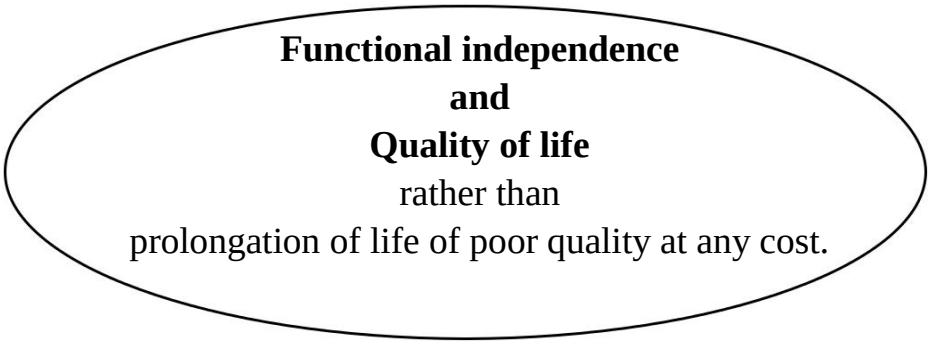
- Investigate only to plan care that may improve the quality of life, not just to make a diagnosis.
- It is important to know the age related variables while interpreting the results.
- Non-invasive tests are preferred, if available.

The older person may be searching for the meaning of life while trying to cope with losses of close friends and relatives and a sense of worthlessness. Death may no longer be a distant vague possibility, and can be the source of persistent anxiety. Routine screening for spiritual despair, delirium, depression or dementia can uncover these common issues

Goals of care in elderly

- Enabling functional independence
- Improving quality of life
- Preventing morbidities from those disorders to which elderly are at high risk – e.g. delirium, falls, fractures, infections
- Preventing neglect and abuse
- Maintaining dignity and self-worth
- Address family and caregiver issues

Goals of care



When planning care, we shall keep asking ourselves: will this step help the person to improve functional independence and quality of life? If there has been an acute deterioration, then effort must be to bring it back to the level prior to the acute condition. In chronic progressive conditions, the aim is to reorient expectations to realistic levels, optimize the medical condition and make arrangements for maximum functional independence and support for patient and family to endure the situation.

Pain relief in elderly

Pain is often not expressed and needs to be elicited through direct questions. In patients with cognition dysfunction, visual pain scales are used to decide if analgesic therapy is required.

Medications

It is important to check renal/hepatic function and reduce the dose when needed.

Polypharmacy is common which can in turn lead to drug overdose, drug interactions and poor drug compliance. Regular review of the medications can prevent these issues and reduce the out-of-pocket expenses.

Non-adherence in elderly can be due to cognitive impairment, complexity of the regime, more than one prescriber or poor understanding of the disease and the medications.

Pain management:

The principles of pain management are the same as in younger adults, remembering particularly that:

- NSAIDs are often poorly tolerated due to greater incidence of gastric and renal dysfunction. If essential, use gastroprophylaxis and avoid dehydration.
- Opioids may be the safest agents, but the dose and frequency of administration must be decided based on renal dysfunction. For example, in advanced age, it may be prudent to start with morphine six hourly rather than the customary four hourly.
- Dehydration is an important factor for toxic side effects of opioids and needs to be corrected while titrating opioids.

Advice on nutrition with emphasis more on the quality rather than the quantity can be useful. Every consultation should also be considered an opportunity for preventing further deterioration.

Preventing further deterioration

- Life style modifications – high nutrition diet, alcohol, tobacco
- Exercise – physical and mental (for example, reading)
- Use of physical aids (walker, cane) since some medications such as opioids or antidepressants may increase falls
- Supplements – Calcium, Vit D
- Vaccinations
- Polyvalent Pneumococcal vaccination during 1st consult and every 10 years
- Tetanus

References

1. Situation Analysis Of The Elderly in India [June 2011] Central Statistics Office, Ministry of Statistics & Programme Implementation, Government of India