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PALLIATIVE CARE IN INDIA

For freedom from pain

In India, where terminal illnesses like cancer are often detected too late, how many patients get to see a palliative care specialist to help mitigate pain and other socio-psychological trauma? Palliative care doesn't reach people who need them because it continues to be a neglected speciality, says **DR. PRIYADARSHINI KULKARNI**

Naina Patil (name changed) may not be aware that another World Cancer Day has come and gone. It has been a decade since she was diagnosed with chronic myeloid leukemia (CML). At 20, she is a bright and cheerful girl, doing her second year in BA and looking forward to becoming a fashion designer.

Such an aspiration was probably the last thing on her mind when she was admitted to my Centre about three years ago. She was confined to a wheelchair, contorted with pain and scared about life. Over the next few days, the transformation was dramatic. The girl who could not walk was merrily riding a bicycle.

There has been no miracle. Sad as it is, the cancer within her is getting worse. Just a few days ago, she chose to celebrate her birthday at Cipla Centre, her "second home". Her entire family was around. Everyone present, including other patients and their relatives, fed her a piece of cake and then wiped a tear out of her sight. We do not know about her next birthday. What we do know is that thanks to palliative care, she has regained her zest for life and her smile.

The challenges

The WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." It has recognised palliative care as an integral and essential part of comprehensive care for cancer, HIV and other health conditions. It has urged countries to take action in three areas — policy making, education and drug availability. In India, we face major challenges in all three areas.

It is difficult to put an exact date to this but we believe that palliative care was introduced in India about 20 years ago. According to official estimates, at any given time, 25 lakh people have cancer in India. Almost two lakh new cases are diagnosed every year. Of these, 80 per cent cases are detected too late for any curative treatment to have an impact. About 1.6 million Indians endure cancer pain each year but only a tiny fraction, 0.4 per cent gets relief through palliative care.

Ironically, 80 per cent of the funds under the government's Cancer Control Programme continue to be spent on treatment facilities. The remaining 20 per cent goes towards cancer awareness programmes and cancer detection facilities. Palliative care does not figure here at all, just as it does not figure in our medical curriculum.

My initiation into palliative care happened when I was a student of medicine. Someone close to me in the family was in pain. We tried several doctors but nobody could help her. Finally, when she did get some respite, I could feel the relief as much as she did. Like most other would-be doctors, I did not know what palliative care was all about. But I did resolve to devote my career to pain management. Talk to any palliative care practitioner today

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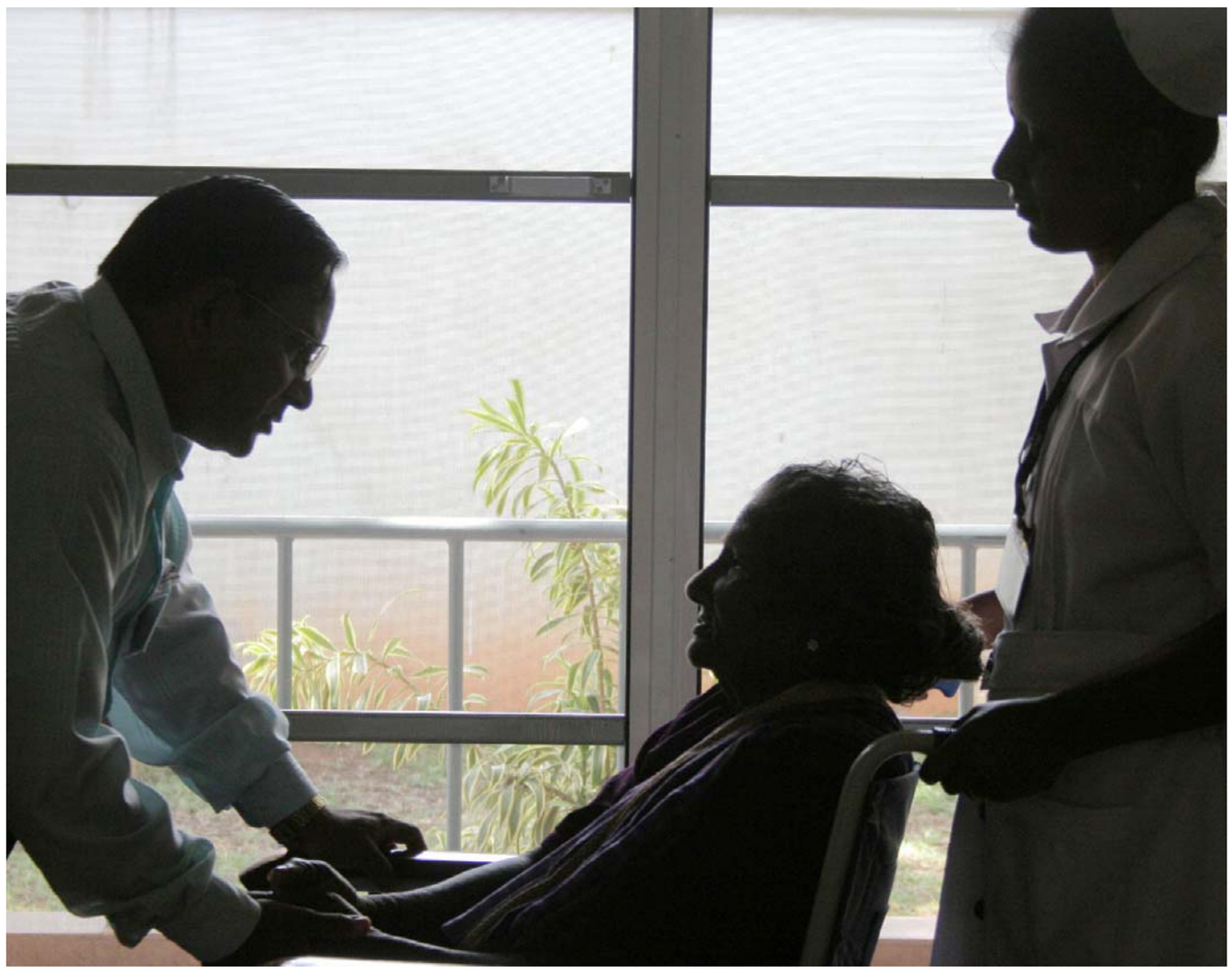
The writer is Medical Director, Cipla Palliative Care and Training Centre, Pune.

See Page 6 for more stories on Palliative Care in India.



TAKING A HOLISTIC VIEW OF TREATMENT... PHOTO: K. ANANTHAN

Kerala shows the way

The State is years ahead when it comes to palliative care policy and implementation...

MEERA PRASAD

Kerala has broken new ground with a palliative care policy that aims at covering every bedridden citizen in the State – rich or poor, down to the last rung. The Arogya Keralam Palliative Care project is being touted as India's first, and the only government initiative of its kind in entire Asia.

Community participation

Flagged off Statewide in 2008, the project got off to a good start in Kozhikode and Malappuram districts in North Kerala. Three years down the line, North Kerala still scores over the rest of the State because of the active involvement of the community there, points out Dr. Anju Miriam John, Medical Officer of the programme in the Kottayam district hospital. "An initiative of this nature can succeed only with people's participation," she stresses.

The Arogya Keralam Palliative Care project is aided partly by the National Rural Health Mission (NRHM). Every district has a core team of a programme co-ordinator, medical officer, nurses and helpers. Smaller teams fan out at the panchayat levels.

The helpers first identify the beneficiaries of the programme through a door-to-door survey. "Once the patients enrol with us, we take them under our wings," elaborates Dr. Anju John. A team comprising two nurses and helpers makes house visits periodically to check on the patients. The doctors step in when there is a crisis. The team also supports the care-givers through the ordeal.

All district hospitals in the State have a palliative care department where the doctors see the patients or their care-givers for follow-up action. Services under the State's palliative care programme are free, even wheel chairs, water beds and walkers for patients. For the very poor, the medicines also come free.

"We want to ensure that all, even the poorest of the poor, with a chronic ailment or an old age infirmity can die with dignity," says Ms. Annamma T.C., sister-in-charge of palliative care services, Kottayam district hospital.

A CAREGIVER'S STORY

Waiting for a miracle

As told to **ARUNA CHANDARAJU**

Thimmayya, 41, is a car-driver in Bengaluru, caring for a wife who has End-Stage Renal Disease (ESRD) and given few weeks to live. He ushers us into the dimly-lit interiors of his house where, in a small windowless room, his wife Shubha is lying on a wooden bed. She looks pale and sickly but manages a weak smile and a faint *namaste* on seeing us. And then closes her eyes as if drained by the effort. A nurse and dialysis paraphernalia are beside her bed.

We come out. Thimmayya tells us his story. He is barely coherent and keeps stopping to compose himself as tears well up in his eyes.

"I came here from Belgaum six years ago for better education for my children. But the health of my wife, already diabetic, began failing rapidly two years ago. From medication to insulin to dialysis and one amputation — she has seen hell and so have we. The dialysis, which began as a once-a-week event, became an everyday necessity and now it's several times a day. She might have a heart attack any time, the doctors say. I have run through all my resources — relatives, friends, current and former employer, charitable institutions... And I am now deep in debt. But what is worse is watching her suffer and deteriorate everyday despite our love and medical care, despite our prayers and vows. She is dying... and we are watching helplessly. I thought my daughter was a brave girl, since I never saw her cry. But when I sent her to my sister's house, before her 12th class exams so she could study peacefully, I realised how little I knew. My sister told me my daughter spent most of the first few days sobbing and was inconsolable. My son has become a poor eater and rarely goes out to play nowadays. People ask me if I have thought about the future. How can I think of anything beyond the present moment and my sinking wife who requires constant attention?"

Living in hope

Thimmayya's nine-year-old son comes out and encircles his father's waist with his arms and looks up at us with a vacant expression. Thimmayya continues: "Miracles happen, my mother used to say when I was growing up. At least for the sake of these children I hope one happens and my wife wakes up healthy one morning. You think God will give us a miracle...?"

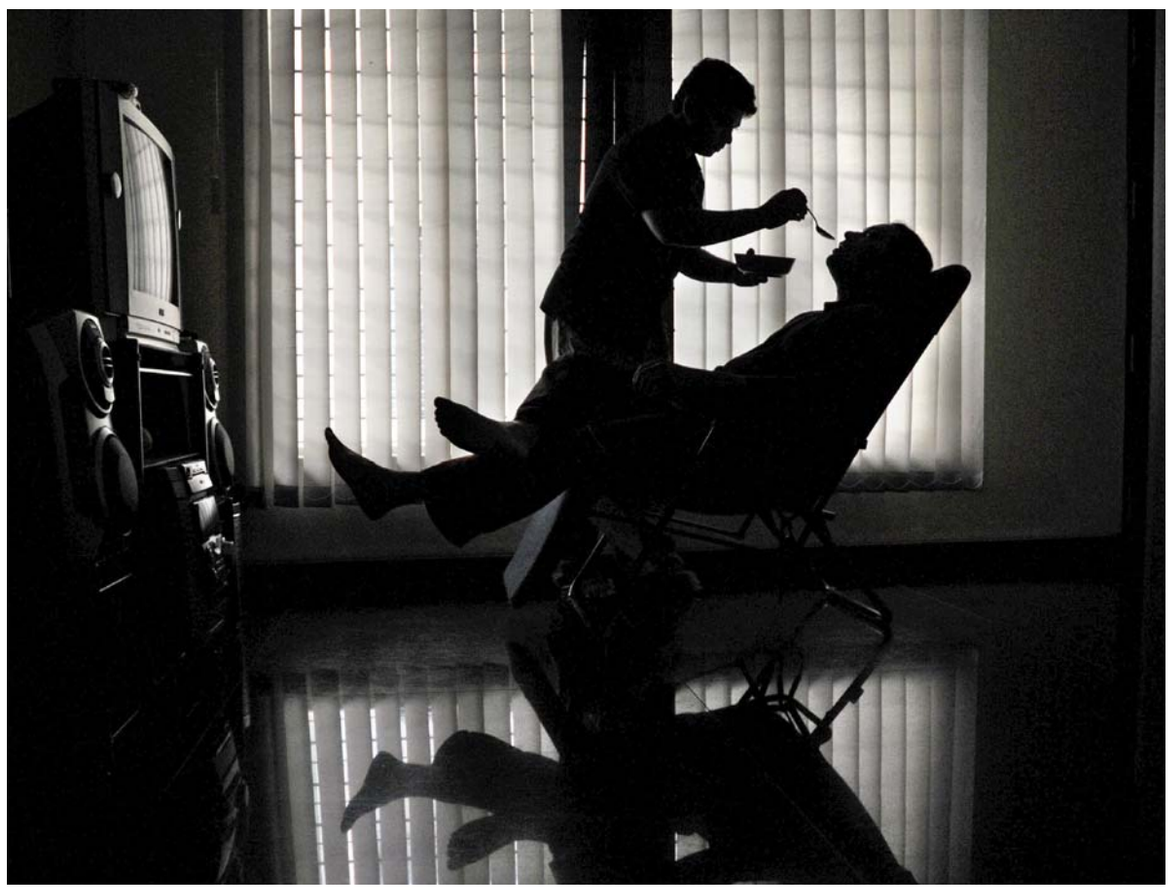
WELL-BEING

PALLIATIVE CARE IN INDIA

The promise of total care

Palliative care is mistakenly understood to be terminal care to alleviate pain when the treatment itself has failed. Treating the 'whole person' for relief from distress and pain should be the goal from the beginning of the treatment itself, says **DR. SUBATHRA MUTHUKUMARAN**.

Medicine is not about conquering disease and death, but about alleviation of suffering, minimizing harm, and smoothing the journey of man.
Strabanek



IT IS POSSIBLE TO EASE UNNECESSARY PAIN... PHOTO: K.K. MUSTAFAH

MISCONCEPTIONS ABOUT PAIN KILLERS AND RESERVING THEM FOR THE TERMINAL STAGE DENY THE PATIENTS THE OPPORTUNITY TO LEAD A PAIN-FREE LIFE...

Mrs. G, aged 56 years, had just completed her treatment for cancer of the stomach. She was pleased with the treatment but was quite dejected that she continued to have pain and nausea throughout the course of her treatment. Actually, Mrs. G need not have gone through this suffering as these *symptoms could have very well been treated even while she was undergoing treatment for cancer.*

Mrs. S, aged 43 years, underwent radiotherapy and chemotherapy after surgery for breast cancer. She thought that everything was alright. A few months later her arm started swelling, making it increasingly difficult to move, much to her physical and mental agony. She thought that nothing can be done and she has to learn to live with it. Unfortunately Mrs. S did not know that *active treatment for this swelling, 'lymphoedema', is possible and should ideally begin early* to get effective relief. In fact, preventive measures are taught soon after surgery.

Palliative Care would have done much to relieve the suffering of both these patients during and after treatment.

Total solution

Palliative Care respects the fact that every human being is made up of body, mind and soul, and should be treated as a 'whole person' when disease strikes, as it is not just the disease but also *the distress* produced by the disease that he (and the family) invariably suffers from.

Palliative Medicine is a specialty which involves the active treatment of patients undergoing chronic and life limiting illnesses. Palliative care is *not just* terminal care. The main focus is on treating the distressing symptoms caused by these diseases *even during treatment of the disease (by the respective specialists).* It is much more needed towards the advanced stage. Palliative care also addresses the emotional, psychological, social and spiritual issues which are commonly seen in these patients. The sole aim of palliative medicine is to improve quality of life.

Acknowledging this 'whole person' concept in treating any patient, the World Health Organisation declared Pain Relief and Palliative Care as the fourth dimension of 'Total Cancer Care' along with the curative options of surgery, radiotherapy and chemotherapy.

So when can palliative care start? The answer is simple – *from the time suffering starts, which could be right from the time the diagnosis* of a disease like cancer is made!

Every patient diagnosed to have cancer may not need palliative care; but the care should be available to all those who need it any time during the course of the illness. At the time of diagnosis: *How does one feel when a cancer diagnosis is made even if it is curable?* The very mention of the word 'cancer' causes fear and anxiety. With advanced literacy and access to information, even if the treating doctor has explained, people have more and more doubts and uncertainties — "Can it really be cured?", "Will it come back?", "Will I suffer in pain?", "Why did God do this to me?" — Classic examples of emotional, psychological and spiritual pain, besides the physical pain. *Palliative medicine addresses these issues which help them cope with the diagnosis and move on.*

Early control of pain and other physical problems can help many to get back to their normal life sooner. At a time when 'Freedom from pain is a human right', it is heart-rending to see patients who have suffered unnecessarily for so long that it is common for them to say, "If you can't take away the pain please just kill me!" They never say this once the pain is taken away!

Pain can also occur during cancer treatment and often patients do not want to continue treatment for this reason. Effective medicine and reassurance of symptom relief help them to resume therapy. *Unfounded fears of addiction and misconceptions about pain killers and reserving them for the terminal stage deny the patients the opportunity to lead a pain-free life and improved chances of survival.*

Decision-making

Sometimes patients with their families consult us soon after seeing their oncologist, simply to get reassurance for 'getting better'. They wish to discuss social and financial matters regarding treatment. Many are willing to sell their life savings or stop education of their children, "if they could only be assured of cure". After listening to all their concerns, we help them to take decisions regarding treatment. We also explain the benefits of cancer therapy and encourage them to undergo the prescribed treatment, assuring our care whenever needed.

Effective communication

Every patient has the right to know about his illness (patient autonomy is an important aspect of medical ethics) but *the way to tell them is important* – neither telling the diagnosis abruptly nor hiding the truth, but gently breaking the news on a need to know basis. Early and effective communication helps both patient and family 'digest' and accept the diagnosis and gives them a direction to move in.

Palliative medicine is not meant only for patients with cancer. Those suffering from any prolonged illnesses like HIV/AIDS, diseases of different organs like kidney, liver, lungs, nerves, will also benefit from it. Palliative care is the essence of all good medical practice. Ideally, all doctors should practise the basic principles of pain relief and palliative care. The subject should be incorporated in the basic medical and nursing curriculum because of the impending need to treat the suffering millions in our country. We believe that this day will not be far off.

Dr. Subathra Muthukumaran is a Palliative Care Physician. Email: lakshmipaincare@gmail.com; www.lakshmitrust.org

Quick Notes

Guided by compassion

Dr. Nagesh Simha, President, Indian Association of Palliative Care, says caregivers need enormous patience and compassion...

ARUNA CHANDARAJU

When is palliative care necessary?

When any disease has gone beyond cure. The commonest cases are cancer, HIV-AIDS, end-stage kidney failure, end-stage cardiac failure, and neurological problems. Palliative care tries to improve quality of life in the last days.

Are treatment facilities in India adequate?

No. Currently, the number of centres offering palliative care in India is grossly inadequate. They cater to only one per cent of those needing it.

Why?

First, lack of awareness among the medical profession and the general public. Second, difficulty in obtaining morphine.

What qualities should a person giving palliative-care have?

Most important — compassion. Then, enormous patience. Finally, appropriate resources.

For a list (not comprehensive) of institutes offering palliative care in India, see:
www.palliativecare.in

For freedom from pain

Continued from Page 1

and you are likely to hear about a similar urge to help ease needless, unbearable pain.

Most of us still tend to confuse palliative care with tender loving care for someone about to die. This is the reason why we think palliative care is the same as hospice care. But the two are very different concepts. A hospice is a home for the terminally ill in the final stages. Palliative care is about ensuring better quality of life through pain and symptom management and through addressing various emotional, social and spiritual issues.

Palliative care does require passion and commitment. But it is as much a specialised science as any other branch of medicine. The developed world has accepted this and already put it into practice.

Many other countries, not all of them developed, have better facilities for detecting and treating cancer. There is also greater awareness about palliative care, as I gather from my colleagues working abroad. For example, at the National Cancer Centre in Singapore, the team that attends to the patient at the time of diagnosis comprises the radiation oncologist, the medical oncologist, the surgical oncologist and the palliative care worker. They are all present at one time and work hand in hand.

How many patients in India get to see a palliative care specialist in the hospital? How many patients are in a better position to go through with treatment and overcome cancer because a palliative care specialist is working with the surgeon or oncologist, to help control the pain and symptoms?

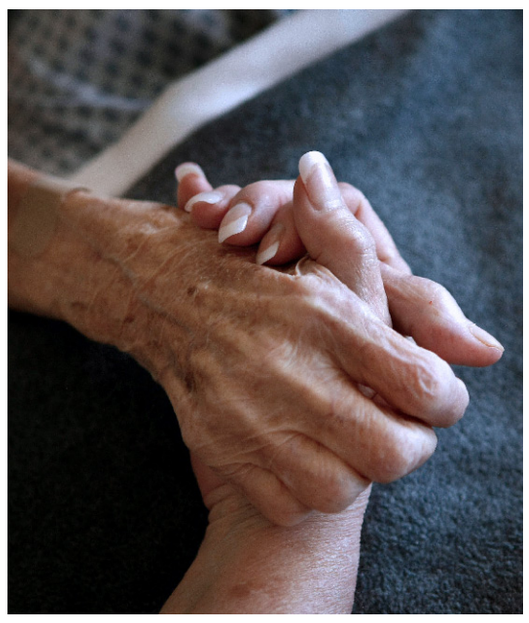
Even the most compassionate medical student in India who wants to consider palliative care as a career option has no options and will have to go abroad to acquire a qualification. The discipline is not recognised as a speciality by the Medical Council of India.

With a small number of healthcare professionals struggling to attend to millions and millions with various diseases, it is difficult for the average doctor to set aside time from his curative practice for palliative care. One of the popular subjects at the training programmes we conduct for doctors at our centre is "How to break bad news". And the most-repeated question is "Why are we not taught in college how to communicate with the patient?" Not surprisingly, one core skill every palliative care team member must have is good communication skills.

Hope for India

For long, it has been our tradition to practise palliative care at home. We believe in the religious care of the dying according to age-old rituals and customs. There was no fear of dying at home because our family ties and bonds were very strong and the family always rallied round to help us tide through difficult situations.

However, times have changed drastically and the "nuclear family" is here to stay. More often than not death happens in hospitals and it is considered as a "failure" of medicine. An aggressive approach towards life preservation with little consideration for the financial and emotional impact on the patient and the family leaves very little scope for palliative care. Perhaps, depending on the diagnosis and the prognosis, it is high time that patients and families started asking for palliative care, possibly along with curative treatment to make things easier for all, especially the patient. Already, some physicians have started recommending palliative care, based on their assessment of the patient and also the overall condition of the family.



THE COMFORT OF A HELPING HAND... PHOTO: AFP

I have come across some unique cases, and each time I have learnt something new from either a patient or a family member. Patients who have lived through unbearable (and unnecessary pain) for months and years come to the Centre and find freedom from pain. When they tell us "I wish I had come here months ago", we think of the millions out there who need help and the enormity of the task ahead of us.

Naina could have been another anonymous statistical dot among the "incurables", waiting for an end to their pain and misery. Instead, for us, she is a lovely young lady, full of life, with definite ideas about fashion trends. We respect her right to freedom from pain. We love her spirit.

She is lucky to be among the minority. The challenge before us is to convert that into a majority. That can happen if all of us, especially the media, speak up for palliative care as a humanitarian cause.

BRIDGE

A brilliant discard!

Connect with friends and sharpen your grey cells.

L. SUBRAMANIAN

The deal below came up in a round-robin among four teams. The successful declarer was V. Krishnan, former Chairman of Bhadravathi Paper Mills. An economics honours graduate from Loyola College, Chennai, he joined the IAS and was Secretary with the Central Government. He is a very keen enthusiast of the game and his charming presence inspires and motivates all. He may be a carefree bidder but more than makes up by his expert handling of the cards. Watch Krishnan at his sublime best:

North dealer, EW vulnerable

W	N	E	S
-	-	-	1♣*
1♠	1NT	Pass	3♥
Pass	4♥	Pass	6♥
All Pass			

*Precision 16+

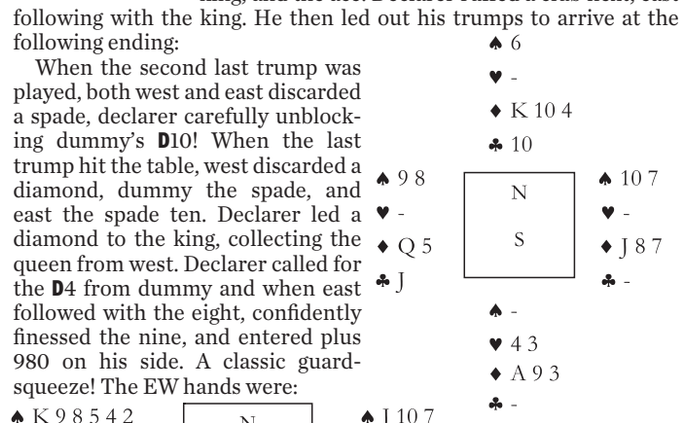
N: ♠ A 6 3 ♥ J 7 2 ♦ K 10 4 ♣ 10 7 6 2

S: ♠ Q ♥ A K Q 8 6 4 3 ♦ A 9 3 ♣ A 5

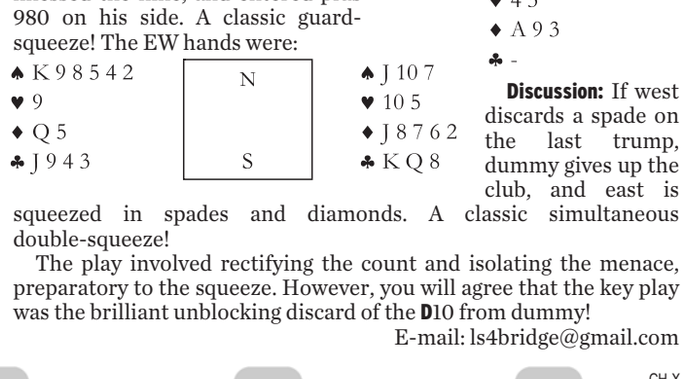
Contract: 6**H** by south. West leads the **H**9, east following suit. Plan the play.

Bidding explanation: With north announcing 8+ points and three-card support for hearts, south wasted no time in bidding the slam.

Play: Declarer won and removed the outstanding trump, west discarding a spade. He next cashed the club ace and exited in a club. East won with the queen and shifted to the spade jack to the queen, king, and the ace. Declarer ruffed a club next, east following with the king. He then led out his trumps to arrive at the following ending:



When the second last trump was played, both west and east discarded a spade, declarer carefully unblocking dummy's **D**10! When the last trump hit the table, west discarded a diamond, dummy the spade, and east the spade ten. Declarer led a diamond to the king, collecting the queen from west. Declarer called for the **D**4 from dummy and when east followed with the eight, confidently finessed the nine, and entered plus 980 on his side. A classic guard-squeeze! The EW hands were:



Discussion: If west discards a spade on the last trump, dummy gives up the club, and east is squeezed in spades and diamonds. A classic simultaneous double-squeeze!

The play involved rectifying the count and isolating the menace, preparatory to the squeeze. However, you will agree that the key play was the brilliant unblocking discard of the **D**10 from dummy!

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