Nursing Standard Nurse 95 Award: Listening to children

[Feature]

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Abstract

Glenn Miles has devoted much of his professional life to working in Cambodia among some of the poorest of the poor.Following a severe head injury, he was forced to return to the UK but he has put his remarkable skills to good use in setting up a child development unit. His work won him The Nurse 95 Robert Tiffany International Award, sponsored by the Royal College of Nursing.

(Figure 1 Figure 2) I believe in nurses. I feel that nursing is a profession that has some very important attributes to offer the world. I feel that we are in an exciting period where, for perhaps the first time in the history of nursing, we are recognising some very important lessons about the value of clients' opinions. (Figure 3)

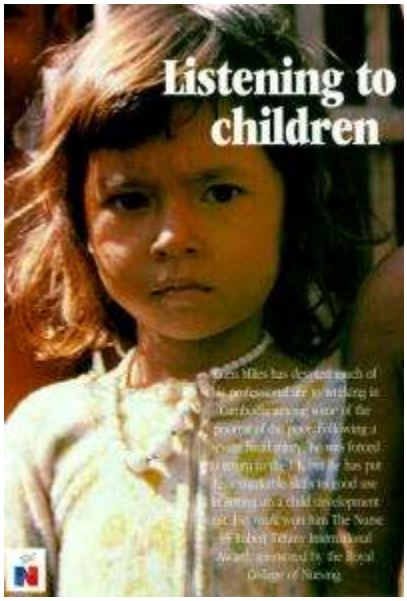

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Figure 3. Above: Glenn Miles; slums are where many of the patients live; a Cambodian clinic; Glenn at the child development unit in the UK.

For some time, as nurses, we have been involving clients in their own care, but now we are taking a step further. The pressure of limited resources is making us ask clients what they want. We are starting to empower clients to be aware of the different options that are available to them, so that they can make informed decisions about their care. We are also starting to include clients' opinions in research. In doing this, projects are made more appropriate and long-lasting.

Not another nurse talking out the top of his head, do I hear you thinking? Well, yes and no. During my first year of nurse training I visited a Salvation Army Hospital in India during a four week vacation. The experience changed my life. Even in that short time I was able to see the potential that an expatriate nurse could have if he or she was able to get to grips with the culture of the people.

When I completed my nurse training, I returned to India for several months and quickly realised that I was ill equipped. I realised that my western style training was inappropriate to the east, even with a short course in tropical medicine. I felt that paediatrics would be more appropriate for a western male than midwifery so I began my RSCN. It wasn't until later that I realised I needed to change my perspective from the western individualistic approach to an eastern community one.

Interestingly, as I worked in a rural clinic in Pakistan on the edge of the Sind desert, I began to realise that in a post-colonial society expatriates have learned that the only way to work is to respect the people's beliefs and opinions. They realise that they need to understand what and why the people are thinking what they are thinking, and then work with them in finding the solution to their own problems.

My next overseas assignment was in the Thai-Cambodian refugee camps. Site 2 North housed 100,000 refugees who were dependent on the United Nations for rice, water, shelter and protection.

When I arrived, the emergency phase was over and a well structured health infrastructure had been developed. It would have been ludicrous to have had 101 expatriates doing all the hands-on work, so training programmes were developed for a variety of different level health workers.

Over a three year period, I had worked with the five Cambodian health directors in developing a community healthcare training programme and helped to set up 21 self-contained health centres throughout the camp.

Each centre had about 20 health workers who dealt with immunisation, growth monitoring, malnutrition assessment and treatment, traditional midwifery, antenatal and postnatal care, child spacing and community outreach. Each worker was able to be repatriated with a clearer understanding of health, if only for their own families and local community. They also learned skills of managing a centre giving back dignity and a sense of ownership in a place where that was sorely missing. It was exciting to be at committees where refugees were able to participate as equals with international health professionals.

The refugee camp was also where I met my wife, an American nurse practitioner and we were married after both our contracts were completed. After we were married, and having spoken at various churches, schools and hospitals in the UK and USA to raise awareness (and money), we moved on to Cambodia itself to work with the Ministry of Health in developing an appropriate health programme for one of the slums of Phnom Penh.

It was difficult to get the right balance between submitting a proposal that the government felt happy about, and what the community felt happy about (not to mention potential donors).

In the end, we felt the most appropriate action was to work out a research project to find out what the local community felt their needs were and then discuss the findings with the local district health officer and health workers. We even lived in a slum house similar to those of the health workers, so we could appreciate some of the reasons why the health workers didn't have quite as much energy and enthusiasm as most of the expatriates.

We chose not to have funding with too many strings attached and we felt that less funding would create more sustainable projects than more funding.

After 18 months the project is going well but we have a way to go. I sustained a serious head injury while in our slum house. My wife was having a miscarriage and I fainted, fell back against the wall and fractured the base of my skull. At that moment I also permanently lost the hearing in my right ear. We were without transport or phone. It took three weeks to get back to the UK and three months to get over the worst of the ataxia. I was unable to work for ten months and am still suffering frequent headaches.

At the time of the accident I felt that my dreams and visions for the future were fading. I felt that my nursing career in the developing world, and even in the UK, had come to an end. Then I was given the opportunity to work in a child development centre with West Lambeth Community NHS Trust.

West Lambeth were looking for someone to set up an information resource centre for parents of children with special needs and professionals working with such families. They weren't sure who they wanted or how it would be set up, but I managed to persuade them that they needed a nurse with experience in working cross-culturally and inter-sectorally (me!).

I emphasised my skills and ability in doing appropriate research and that I was able to manage a budget. Most importantly I felt that I was able to offer my experience of working with parents and professionals as the project developed.

Within a relatively short space of time I was able to do an extensive survey of 1,000 clients (650 professionals and 350 parents) living/working in Lambeth. I had a 15 per cent return rate (100 professionals and 50 parents) and from the results I was able to set up a resource information centre with an emphasis on the areas the clients felt were most important.

Furthermore, I was able to set up a steering committee made up of representatives from community and acute health services, education, social services and the voluntary sector as well as parents. The chairperson is actually a parent. This will ensure that the project moves in the right direction, meeting the needs of all the users.

Talking to the parents, I realised that with my experience of being a victim of a serious accident, I was able to relate to them in a way that I previously could not have done. Once again there was a kind of understanding or dialogue with the client. Listening to them enabled

me better to understand where parents of a disabled child are coming from and what they feel they need.

I am pleased to say that the centre is now up and functioning. Many people have been heard to say: 'I wish this had existed before', or 'I wish I had known about it before'. What better compliment could a project have?

Now one of the parents has applied for my job. If she is accepted the aim of development will have been achieved; to give it back to the people. Also, following a National Child Health conference in June, I have had enquiries from all over the UK from others wanting to set up a similar scheme themselves.

As part of a masters degree in international maternal/child health, I hope to take the themes of development and client participation one step further.

As a paediatric nurse I have often involved parents in the care of their child, on an individual basis. In the resource centre I attempted to involve parents in the planning and decision making affecting the project itself. But what about the children? Could you involve children in planning and policy of healthcare programmes? I have been excited to explore the Child to Child programme which is aiming to do just that.

If you think this sounds exciting in the UK-which it is-then imagine what effect it has in poor communities in the developing world where children are generally ignored and where fate is preordained. I believe that this kind of programme has enormous potential to effect change in these new lives, as they are given the dignity that their views matter.

There is much rhetoric in the Patient's Charter about clients making informed decisions about their care. There is also much rhetoric in the United Nations Convention on the Rights of the Child that children 'have the right to say what they think about anything that affects them. What they say must be listened to carefully.' I believe the Child to Child approach is attempting to tackle both of these in a practical and effective way.

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