International

Silently lost in a sea of infections

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Key messages

- This article highlights some of the problems faced in working in resource poor settings. While the situation may differ from general practice in London, many of the same principles apply.
- It highlights the importance of keeping hearing loss in mind when seeing children with other conditions.
- It shows some of the principles in the Alma Ata declaration, such as the inequity in treatment between developed and developing world settings, health care rationing and the concept of health including social well-being.

Why this matters to me

This article relates to my time working in Pakistani Kashmir for a medical NGO in both primary and secondary care paediatrics. It describes trying to help a young girl with hearing loss. Particularly in a setting like this, you tend to prioritise the immediate problems (mostly infections in infants) and ignore other things however difficult they may be for the child and family. Most importantly I feel this article provides a different perspective, giving a first hand account of dealing with a difficult problem in a difficult setting.

While not directly related to general practice in London, this article provides many important and

relevant messages. Neonatal hearing screening may mean that congenital hearing loss is picked up at birth, but other forms will present at a later stage and children who have not been screened (who missed the screening, parental refusal and those who came from overseas) still need to be considered.

Thirty years on from the Alma Ata conference the world is still blighted by many of the same problems. This personal account shows many of the difficulties spelt out by the declaration. In particular it highlights the persisting inequity in treatment between the developed and developing world.

It shows the importance of health including social well-being. The girl in this story lacked a disease, but being unable to hear, or more importantly communicate, would mean an inability to live an independent life in the future.

Another concept highlighted is health rationing, which is faced almost daily in any field of medicine. This is especially so in fragile states and war zones. External health funding goes predominantly to 'fashionable' diseases such as HIV, which has led to organisations trying to promote the 'neglected' diseases, for example trypanosomiasis. Despite its debilitating effects hearing loss achieves even less attention than these.

Keywords: hearing loss

It is a usual morning clinic. I am hungry and tired and reaching my nadir. Unfortunately though my clientele of screaming infants do not appreciate such trivialities. I sit in a tent full of people in this makeshift hospital in Kashmir treating infection after infection. I slip into auto-pilot, always a dangerous thing, while my translator asks a standard set of questions.

A chest infection I diagnose confidently. 'He'll be OK. Just take these tablets for a week and come back if he's getting worse.'

'Who's next on the treadmill?' His mother starts to get up and then pauses. She speaks to my translator in a hushed tone, embarrassed that there should be

something else. 'Apparently her daughter cannot hear' the message is relayed back to me. Feeling the pressure of the hordes pushing to get in, I hurriedly look around for her daughter. I spot her in a corner at the other side of the tent. She looks up at me with a sparkle in her eyes. She smiles and I smile in return. I automatically feel happier.

Assuming some wax or fluid in her ears, I beckon her closer. 'She is nearly three and has never been able to hear', her mother reports. My level of concern rises a notch. 'Really? Is that true?' I reply, somewhat sceptical, but staying impassionate.

'Yes and her other brother cannot hear as well.'

I watch her playing. Unfazed by the commotion around her, she is engrossed in her task of splashing chlorhexidine around the table with a spatula. It is only then that I notice how quiet she is.

Alarm bells are ringing. This might not be a simple conductive hearing loss. I question her mother in more detail. Sure enough it turns out that she has never been able to hear and neither has her older brother. My barrage of questions yields few results except that her parents are related (not an unusual phenomenon here).

‘Apart from her ears, she is OK.’

I then try to perform a ‘distraction test’; a surprisingly difficult feat in a crowded clinic. I scrunch some paper. No response. I move on to banging a cup. The whole clinic stops and everyone stares at me. Everyone, that is, apart from my little girl. I sit back and watch her playing with the otoscope, her shining face, silent in this sea of infections.

She appears to have a severe, bilateral, hearing loss; probably congenital. I would normally refer her to audiology and she would get some hearing aids, speech and language support and maybe even a cochlear implant. I do not know what is available here. It is almost certainly too late for her brother; he may never develop meaningful communication skills. But we might be able to help the little one. The auditory system is sensitive to neural activity till about two years old, after which the link weakens.^{1,2} So at this young age, even if she cannot hear, she should be able to learn to communicate. There’s no time to waste.

‘What can we do for her?’ I consult my colleagues who stare back at me blankly. Trying to buy some time I ask her to come back tomorrow. Thankfully they live nearby so this is not a problem. Her mother seems happy that I am taking this seriously while others have dismissed her concerns in the past.

What does the future hold for this little girl? I wonder. She seems to have a very caring mother, but will she ever be able to leave the family? Will she be able to get married and have her own family? Will she ever be independent?

Later in the day I call my boss at HQ. ‘We need to check her out properly. Maybe some hearing aids? Some language support? It is so important at her age.’ He listens. He agrees. He refuses. ‘We are in an emergency. We can’t help with things like this.’ I don’t blame him. I might well have made the same decision if I was in his place, but we seem to spend money in so many other unnecessary ways.

‘Does deafness matter here?’ It seems unfair that this little girl is being ignored, but priorities are different. Particularly after the earthquake, there are more pressing concerns. With around one in ten children under the age of five dying in Pakistan, to survive childhood at all is a difficult task³ and hearing loss is certainly not one of the fashionable disabilities for

donor funding. It does not even achieve the notoriety of being one of the ‘neglected diseases’.

Forlornly I go to ask my nurses. They seem more optimistic. ‘There is someone in Islamabad; an expert.’

The next day I hear some commotion outside the clinic. Our Crowd Controller is berating one of the mothers. ‘She wants to see you and not one of the other doctors’, he tells me. ‘The foreign one.’ I see my smiling little girl peeping around the curtain.

‘Can you explain to her that she needs to see this person in the capital’, I ask, writing down the name of the doctor previously given to me and handing her my referral letter. While the nurse discusses with the mother, I play hide and seek with my patient.

I wonder if I am doing the right thing by sending her to Islamabad. They will probably just say that nothing can be done. ‘First do no harm’ we are taught as a basic tenet of medicine. Am I actually causing trouble for the family and unrealistically building up their hopes? Am I clinging to unrealistic hopes myself?

Time passes and the daily pressures take over again. The weather has changed with a drop in temperature and whole days of rain. I am back in the clinic again, only this time with a heater next to me. Dodging the Crowd Controller she runs up to me. Her face bright as ever, she hands me a file. Her mother confidently follows on behind. The file contains her medical notes from her appointment in Islamabad. Eagerly I open it; my heart sinks. She didn’t see the expert at all. She was stopped at the first hurdle by a junior doctor who gave some decongestants and sent her away. Her mother is happy, optimistic that her little daughter will be able to hear soon. What can I do now? I can’t send her back again. I have no control over what happens there. Maybe I was wrong? Maybe decongestants are the answer? For want of a better alternative I ask her to try the medications and come back in a week.

During that week one of the nurses fortuitously spots a new ‘audiology clinic’ in a nearby city and I even manage to convince my boss that we should send her there. This time I call the doctor first. He seems very enthusiastic and reels off a string of qualifications trying to impress me. He succeeds. Cynically I assume that he sees me as a source of business.

She returns a week later as requested. Her mother is a little more subdued this time. Is she wasting her time coming to me? While my patient returns to her chlorhexidine splashing, I tell her mother about the new doctor who will be able to help her. She smiles, doubting, but with some renewed hope.

I never see my smiling little girl again. Has her mother finally given up with us? I check with the other staff, but no-one has seen her. I call the audiologist again and again and eventually get through. Yes he saw her and yes she is profoundly deaf. I explain our situation that I, and the whole organisation in fact, are leaving soon and that I have not seen her again. ‘It’s OK’, he

says reassuringly. 'I'll take care of her.' He explains to me that they are trying to teach her and her brother non-verbal communication. 'And what about the money? They can't afford the care.'

'Oh we will just get another charity. Or treat her for free.' It seems that she has weaved her spell over them as well.

Contented I close this case in my mind. Hopefully with the help of her new team she will develop some language skills and, even if she cannot hear, will 'swim' towards an independent life in the future.

ETHICAL APPROVAL

This is a personal account, with no patient identifiable details.

CONFLICTS OF INTEREST

None.

REFERENCES

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