

A tweet a day keeps medical ignorance away!



By day she is a hotshot information technology professional at one of multinational top telecom companies. But by night she volunteers to promote public understanding of something totally unrelated - the rational use of medicine.

For Alifah, 32, the two worlds are easily bridged by the simple fact that in both it is her expertise in handling large communication networks that plays a key role.

“Immunisation, breastfeeding, antibiotic resistance - these are the themes we reach out to our audiences with,” says Alifah, who is the Social Network Coordinator for the Yayasan Orangtua Peduli (YOP), a Jakarta based group that educates Indonesians on important health issues and is also a partner with ReAct on the global Civil Society Organisation project.

Starting off in 2003 as a simple email list sending out information to parents of young children on pediatric illnesses the YOP’s social network now consists of Twitter accounts, webs and Facebook pages accessed by thousands of people around the country.

While the email list, called Milis Sehat (sehat@yahoogroups.com), now reaches over 17,000 people, the ‘GESOBAT’ Facebook group that deals with rational use of medicine has 10,000 members and the ‘GESAMUN’ Facebook group has over 43,000 members. The YOP’s Twitter account (@milissehat) has the widest reach with 35,500 followers all over Indonesia.

“It is a very heavy traffic mailing list, where parents talk to each other, support each other, share links and articles about medicine, antibiotics, about illnesses,” explains Dr. Purnamawati Pujiarto, a pediatrician, health activist and the brain and soul behind YOP. On an average the Milis Sehat list gets around 100 emails a day, most of which Dr Purnamawati responds to personally.

Through the intense exchanges on these various social networking platforms the patients start to be exposed to the latest guidelines and to the concept of evidence based medicine. They are also exposed to the concept of patient safety. Many of the members are young parents in the age group of 25-40 years of age.

“We use guidelines and information from trusted websites such as the Centre for Disease Control (CDC) in the United States or the World Health Organization,” says Alifah, who also moderates all the social networking

platforms to respond to questions, direct people to the right information sources and do troubleshooting. All the information generated by these networks are archived systematically in a database for easy use and future reference.

“Though it is not a problem unique to Indonesia, antibiotics as popularly regarded as ‘magic saviours’, says Dr Purnamawati pointing out that regardless of what the problem is, they believe, antibiotics will deal with it quicker and better.

According to Dr Purnamawati for pediatric populations the use of antibiotics is very high for three conditions: fever, common cold and acute diarrhea. For upper respiratory tract infections the prescription of antibiotics is over 60 percent. Prescription is often dominated by non-generic antibiotics and non-first line antibiotics, she says.

A 2009 study¹ that surveyed two hospitals in Surabaya and Semarang showed that depending on the type of department between 67% (Internal Medicine) and 90% (Surgery and Paediatrics) of patients who are hospitalized for at least 5 days are treated with antibiotics during their stay in hospital. Only 21% of prescriptions were considered appropriate, for 42% there was no indication for treatment and 15% were inappropriate regarding choice, dosage or duration. Fever was often the trigger for starting antimicrobial therapy, even when no obvious signs or symptoms of bacterial infection were present or even a viral infection was likely.



Interventions, such as the one by YOP are helping increase awareness about antibiotic resistance and related issues amidst the Indonesian public. On the Milis Sehat email list very often the questions posed by members are answered by other members, some of whom have specialised knowledge of subjects such as infectious diseases, antibiotic resistance or immunization either due to professional involvement or personal interest.

“Indonesia has the largest number of Blackberry users in the world! Mobile phones are the fastest way to reach people with all kinds of messages,” says Vida Parady, YOP’s communication officer. Tweets, email, Facebook pages- all are accessed over mobile phones and shared across vast networks in a matter of minutes, she points out. According to YOP staff they have found that the Facebook platform facilitates change of opinion the most as it involves

¹<https://openaccess.leidenuniv.nl/bitstream/handle/1887/13821/07.pdf?sequence=12>

multiple participants and greater chance of building consensus through discussions.

In addition to IT-based ones YOP also has more hard labour based communication strategies, like for example educational seminars, where members meet once a month, in several cities. Typical themes discussed include patient safety, safe use of medicine, how to be a smart patient, what questions to ask doctors and common misconceptions patients have about health, disease or medicine.

YOP also has its own publications such as books, brochures and pamphlets besides using the space offered by media tabloids and newspapers for dissemination of health information. YOP volunteers also prepare radio programs for reaching out to the vast urban and rural audiences in Indonesia. Occasionally YOP also gets a slot on TV talk shows but regular programs are not possible because of the high costs involved. All media coverage, TV and radio programs, as well as print/online media publications, generated by YOP, or involved YOP, is not paid for and does not cost it any money.

Box: IT-based education and behaviour change

A YOP study to evaluate the impact of IT-based education on rational use of medicines among its mailing list members found significant changes in their information base and behaviour.

For example the percentage of members improving their knowledge of causes and treatment of fever jumped from 6.6 % to 53.8 % after attending YOP's educational classes for six months. Similarly for upper respiratory tract infections and use of antibiotics the figures increased from 18.3% to 100% and 3% to 97 % respectively.

The study was carried out from February to October 2010, involving 197 parents who subscribe to the members of sehat@yahoogroups.com mailing list. The findings demonstrate that the intervention through education done by IT-based channels have been effective in increasing the members' knowledge and changing their behavior towards a more rational use of medicines. The key findings are presented in the table below:

| Knowledge on various topics | Before (%) | After (%) |
|---|------------|-----------|
| Fever | 6.6 | 53.8 |
| Cough and upper respiratory infection (URI) | 18.3 | 100 |
| Acute stomach flu (GE) | 14.2 | 98.5 |
| Antibiotics | 3 | 97 |
| Use of antibiotics for URI | 64 | 3 |
| Use of antibiotics for GE | 40 | 1 |
| Use of antibiotics for fever | 87 | 6 |

| Changes in behavior | Before (%) | After (%) |
|---|------------|-----------|
| Management of fever: | | |
| Importance of liquid | 2.5 | 98 |
| Avoid using paracetamol for low-grade fever | 21.3 | 93.9 |
| Management of URI: | | |
| Use of expectorant and antitussive | 75.6 | 0 |
| Use of bronchodilator medicines | 67.3 | 2.3 |
| Management of acute GE: | | |
| Anti-diarrhea medicines | 48.7 | 0.5 |
| Antiemetic medicines | 20.2 | 0 |
| Oral rehydration solution (ORS) | 8.6 | 94.4 |
| Reduce use of <i>puyer</i> : | | |
| To manage fever | 76.8 | 2.1 |
| To manage URI | 79.7 | 1.5 |
| To manage acute GE | 41 | 1.6 |
| Find information on medications/treatment: | | |
| Through medical doctors | 17 | 24 |
| Internet | 6 | 64 |
| Do not look for information | 34 | 8 |

Interview with Dr Purnamawati S Pujiarto, YOP

Can you tell us about the activities of YOP?

Wati: YOP is an abbreviation for Yayasan Orangtua Peduli. Yayasan is a Foundation. Orangtua means 'parents' and Peduli means 'caring' or 'concern'. Our Foundation consists of members/patients who care for the future generations. Our vision is that children deserve the best standard of treatment. That patient safety should be addressed through multiple angles. And patients themselves should be fully aware about what patient safety is and their own role. Patients should be involved in improving quality of care in regard to patient safety. When we talk about patient safety this also means the technical aspect, very medical aspects such as safe use of medicine, safe use of antibiotics. Therefore our core project is to educate the patients so that they can be wonderful partners to health providers.



What are the kind of methods you use to raise awareness?

Wati: We use several kinds of strategies. We very much use IT-based campaigns. Indonesia is so big and we are scattered among so many islands. How can we reach people otherwise? We develop mailing list. It is a very, very heavy traffic mailing list, where parents talk to each other, support each other, share links and articles about medicine, antibiotics, about illnesses. So the patients start to be exposed to guidelines, to evidence based medicine through this mailing list.

The second IT based platform we use are websites. Often these are not updated very regularly because don't have enough resources, but we try. We get new, young doctors these days as volunteers so we hope we can get better with the website. The third IT based strategy is through social media - Twitter or Facebook. We spread messages regarding safe use of medicine and antibiotics also including preventive methods. Like for example the importance of immunisation, about breastfeeding, complementary feeding, nutrition. This is because if we are talking about patient safety we cannot speak only about the curative side but need to speak also from the preventive side.

Can you tell us something about the 'puyer' tradition of dispensing medicine in Indonesia? How widespread is it?

Wati: In Indonesia, the *puyer* (Dutch word for 'powder') is used especially with children, but nowadays with adult patients also. Many Indonesian doctors believe that when a child is sick and needs several medications it is better to prepare it in a powder form. Probably this was relevant several decades ago when pediatric formula was extremely limited. However, up till now, 90

percent of pediatric patients- when they are sick- get this puyer, which in Dutch means 'powder'. But in medical terms it is a compounding medicine. For example if a child has fever, cough, cold, running nose then he or she will be prescribed antibiotics, antifever, mucolytic, anti-histamine, steroid, bronchodilator, anti-congestant like ephedrine/pseudoephedrine, etc. And how to give those medicines? They crush it.

Initially people believed that by crushing these small doses of medicine you are being more efficient because you share the tablets with other patients. For codeine for instance, you need only a very small dosage so one tablet can probably be shared among several patients. But through evidence based medicine we learn guidelines of diseases. And mild illnesses like upper respiratory tract infections, acute diarrhea are mostly self-limiting because those are viral infections and the children do not need many medicines';. Through our study about URI in several cities we found people were getting many kinds of medicine. One child got 26 different kinds of medicine! So they crush all those medicines and then they put it on a small piece of paper. Nowadays they are more sophisticated so they use the blender and machines to develop the sachet but still the main concern is if you follow evidence based medicine children should not be getting over two or three medicines at the most.

Second, if you follow good manufacturing process, dispensing medicines has its own rules and regulations. Crushing all those medicines, opening the capsules, pouring the contents and mixing with slow release tablets, all this is not manufacturing process that is good and safe. It is prone to hygienic problems, it is prone to technical error, dosing error. And the other concern is that the active ingredients are no longer stable. And what trouble can be expected if the drug is no longer in good?

What is the kind of experience YOP has had through its interactions with ReAct and its network in the region?

Wati: In 2011 I got a mail from Michael Chai, S.E.Asia Coordinator for ReAct. I did not know what ReAct was at that time. I was so glad ReAct was able to locate me and here we are today with a dedicated program on antibiotics as part of our patient safety work. When I heard of the Antibiotic Smart Use project in Thailand, I was so jealous and thought 'when can Indonesia have a program like that of its own?'. So after going to see the ASU project I came back and sat with parents in a very big auditorium and shared with them my experiences in Bangkok and said 'let us start working on antibiotic resistance'. Everybody contributed in their own way to develop the core message, based on the experience of Thailand- 'do not take antibiotic for cold and diarrhea'.

Initially, we did have a problem with acceptance of this message, especially in the context of diarrhea. Some health providers objected to that message. Hopefully with time things will become better. However, we have learnt a lot from the Thai experience as also the Antibiotic Stewardship program in

Singapore. I have also learnt a lot from the studies done in Vietnam. Our problems are a bit similar. We do have problems with our pharmacy outlets. Most pharmacies in Indonesia are not very exposed to new knowledge and are not yet implementing the good manufacturing process.

I hope ReAct continues exploring this kind of collaboration with groups like ours.



Vida Parady, Communication Officer, YOP

How do you use social media for spreading information on antibiotic resistance?

Vida: Our main platform for dissemination of health-related information is Twitter. On some days of the week we focus on antibiotic resistance. We use a hashtag in Bahasa Indonesia, which translated into English means 'prudent use of antibiotics'. Whenever we want to tweet about antibiotic resistance we ask our friends from the Milis Sehat mailing list, who happen to have a large number of followers, also to retweet the message. Or when they send their own messages on this subject they need to mention @milissehat so that we can retweet it.

We try to find and identify some members who have thousands or even hundreds of followers and ask them to generate messages about antibiotics. We also share links or articles through our mailing list. Most of them are in English. We ask mailing list members who have twitter accounts to spread the message. Recently we have compiled a list of Frequently Asked Information, where the answers are less than 140 characters that can be copied and pasted on Twitter by members of our mailing list. On Facebook we do basically the same. Now that we have the ReAct website also we just download or copy the links and send them around also.

What are the numbers of people you are reaching through this?

Vida: For Twitter it is about 35,000 followers. On Facebook we have different pages, but no dedicated page on antibiotics as yet. We have a 'Smart Use of Antibiotics' website also. But on our mailing list the number of emails related to antibiotics has been growing. I would say that at least we have a couple of messages on antibiotics every day. Previously people discussed whether they need antibiotics for a particular condition/illness but now we have discussions on antibiotics in other contexts. The discussions are also not just confined to illnesses of kids but also adults. One of our moderators, he is very updated about information on the web so he always forwards information he gets from CDC or news articles on antibiotics he comes across.

What is the advantage you find in using social media?

Vida: It is definitely the reach as people can access social media through their mobiles. Indonesia has the largest number of Blackberry users in the world! That's how they get all the tweets, the email from the mailing list. It is fast for responding, spreading or sharing information.

What other communication strategy are you following?

Vida: We want to make people aware of the wider implications of the issue. So far we have been talking about antibiotics as a cure and about when to use or not use antibiotics. The ReAct Latin America conference in Cuenca, Ecuador in October 2013 I attended was really an eye opener in terms of the different techniques of communication possible. We want to make our communities aware that this is a global issue and much more than about curing a disease. There is so much we can actually do at a global level and not just within our own individual countries.

