

In memoriam: Endang Rahayu Sedyaningsih was committed to research

Rosalia Sciortino, Singapore | People | Fri, May 04 2012, 10:30 AM

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In these times of rhetoric and public relations, examples of people whose deeds follow their words are increasingly rare. Indonesia has been fortunate to have one of such “rarities” in the person of Endang Rahayu Sedyaningsih who passed away on Wednesday of lung cancer.

Her commitment to research and public health for the benefit of society, particularly vulnerable groups, has been reflected in the way she lived her professional and personal lives. Her early research focused on a disease and an affected group that were both despised by society.

She immersed herself in the lives of sex workers in Jakarta to understand how they were being exposed to HIV by clients who did not want to use condoms and how, in turn, this unsafe sexual behavior contributed to spreading of the disease. Loyal to her conviction that knowledge, to have an impact, had to be shared, she worked patiently at translating the results of her research into a book in a writing style accessible to the general public. Perempuan-Perempuan Kramat Tunggak (Kramat Tunggak Women, referring to a red-light district) is to this day one of the most powerful accounts of how socio-economic and gender inequities foster the spread of AIDS.

The same belief in the value of open knowledge brought her to contribute with her research to the global fight against bird flu. In recognizing that the problem was not contained by borders, she understood that the population of Indonesia as well as that of neighboring countries would be better served if scientists shared information and worked together in finding a solution so as to make more effective use of scarce resources and gain life-saving time.

Confronted with nationalist prejudices, she still maintained her integrity as a scientist, choosing to collaborate with foreign colleagues and institutions even if it exposed her to suspicion and allegations of disloyalty.

Transparency and devotion also accompanied her when coping with cancer. When the news of her disease was, in breach of medical-ethical conducts, leaked to the media, she did not choose to disappear into anonymity as most of us would have done, nor did she opt to concentrate solely on her treatment. On the contrary, she decided to remain health minister and serve the country and its people to her very last days.

In a moving private conversation last year, she confided that carrying out her duty made her days more precious and meaningful, and that the challenge of fighting cancer strengthened her in enduring a not always sympathetic political environment and other work difficulties, since these paled in comparison.

She continued to keep to an onerous schedule, traveling across the country incessantly while trying to move complex policies forward and installing an evidence-based culture in the ministry and other health-related institutions. With her performing at the highest level, she demonstrated that sick people have a lot to contribute and it would be a loss to society if they were relegated to inactive roles in society.

In the same way, she had opposed the barrage of negative attitudes towards people with AIDS and other discriminated groups, she confronted the stigma still associated with cancer and raised awareness of it among the Indonesian public. Her ability to “normalize” cancer while bringing attention to the need of preventing and controlling it is her last tribute to the tenets of public health education, a tribute that will be long-lasting in its improving and saving many other lives.

— **Rosalia Sciortino**

Regional director of the International Development Research Centre for Southeast and East Asia, Singapore. - See more at: <http://www.thejakartapost.com/news/2012/05/04/in-memoriamentang-rahayu-sedyaningsih-was-committed-research.html#sthash.aMTE0NZu.dpuf>