

Calling out and preventing enacted stigma in health care encounters: Lessons from women cervical cancer patients and health professionals in Indonesia

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Background:

Cervical cancer mortality in Indonesia is unacceptably high, with a current survival rate of only 50%. This stems from slow progress in primary and secondary prevention, delayed treatment, and low treatment uptake. In the Indonesian context, cervical cancer is also a highly stigmatised disease. This paper examines how cervical cancer related stigma occurs in health care encounters, typically at the point of diagnosis, and violates women's rights.

Methods:

An ARC funded ethnographic study was conducted in Indonesia from 2019 to 2021, producing case-studies with 30 women affected by cervical cancer, and fifty interviews with health professionals engaged in cancer care. Multi-level thematic analysis was conducted using NVivo.

Results:

This paper identifies occurrences of enacted stigma that occurred when women were perusing diagnosis, receiving diagnosis or seeking additional information, and discusses the impacts on women. Stigmatising narratives included blaming women's husbands or women for the disease, emphasising risk factors associated with sexual impropriety and lack of female hygiene, and discriminatory hospital protocols for informed consent. Women's reports of enacted stigma were corroborated by health professionals. Two distinct patterns of response emerged among health professionals: one being to agree that stigmatising practices were harmful and could be avoided through adopting non-stigmatising language, providing accurate information on causality and avoiding blame; the other response was to perpetuate stigma via the use of highly moralised language, a focus on sexual impropriety and emphasising discourses of blame.

Conclusion:

Empathic health professionals identified feasible strategies for developing standards of patient communication and education that can avoid stigmatising cervical cancer patients. These strategies focused on: normalising HPV infection as common among married couples; emphasising long-term HPV infection as a necessary cause of cervical cancer, rather than risk factors associated with sexuality; avoiding all discourses of blame; and removing discriminatory content from consent forms and information pamphlets.