

Dying at life's beginning: an invisible tragedy

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Wednesday, 14 October 2015, 17:30 to 18:30 TN E0.54, Technikumstrasse 71, 8401 Winterthur



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Valerie Fleming

Valerie has been a midwife since qualifying in Aberdeen, Scotland in 1979 and has practised in various countries in Europe, Asia, Australasia, Africa and the Middle East. She undertook her higher education in New Zealand, gaining Bachelor's, Master's and Doctoral degrees from Massey University. She has been active in research and international development since gaining her fist academic post in 1991.

From 2007-2011 she was director of Glasgow Caledonian University's World Health Organisation Collaborating Centre and during the last two years, Secretary General of the WHO Global Network of Collaborating Centres. During this time she received many research and development grants. From 2011-2012 she was Regional Adviser for Nursing and Midwifery, the WHO Europe's highest position in the field. During this time, she worked as a consultant in the Institute of Midwifery, Zurich University of Applied Sciences (ZHAW) and in 2012 took up a full time position there, returning to full time research. She continues to attract research funding.

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The disclosure of a diagnosis during pregnancy of a fetal malformation incompatible with life normally comes completely unexpectedly to the parents. While a body of international literature has considered the topic, there is little evidence generated in Switzerland. Our study "Dying at life's beginning"* aimed to illuminate contemporary treatment associated with such diagnoses regardless of whether parents decide to terminate or continue the pregnancy. This lecture will present an overview of the findings as applicable both to affected parents and to health professionals.

The theme of "temporality" was identified by the professionals with four main time points: diagnosis, decision, birth/death and afterwards. Underpinning this, six themes generated from parents extended across the span from receiving the diagnosis until the interview: shock, choices and dilemmas, taking responsibility, still being pregnant, forming a relationship with the baby, letting go. While there was concurrence on many aspects of care at the point of contact, parents expressed major issues as gaps between the points of contact.

This presentation will illuminate some of the strengths and weaknesses of the present care system and offer several recommendations for future care and research. Research fellow Franzsika Parpan will illustrate the lecture with some of the most moving extracts from the interviews.

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^{*}The study is part of the National Research Programme NRP 67 "End of life"