

Women who suffered COC-related cerebrovascular events: views on CVD risk communication from a UK stroke forum

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One of the advantages of the internet is that patients use it to talk in a public domain about health problems in an informal, off-record manner. The result is the potential for access to the authentic patient voice. This letter reports briefly on how patients who suffered from stroke contributed to an online forum about CVD risk.

We searched the 2004-2011 archives of Talkstroke, the online forum of the Stroke Association consisting of 22,173 posts from 2,348 users. Our aim was studying whether survivors of COC-related strokes were amongst forum users, and whether they expressed views on the communication of stroke risk by clinicians who started them on COC. The analysis was performed using AntConc3.2.4, a corpus analysis software, searching terms related to oral contraceptives.

Thirteen users discussed COC-stroke in 17 posts. 9/13 were survivors of a cerebrovascular event caused by COC, (mean age at event 29 years), who contributed with a total of 481 posts. 7/9 had strokes, 2/9 TIAs. 7/9 had no CVD risk factors at the time of the event, 1 was a smoker and 1 was later found to suffer from PFO. 7/9 mentioned their event being put down to COC, without further discussion or comments from other forum users. There was no mention of stroke risk being inappropriately estimated by clinicians. 2/9 complained with one another of not being warned about stroke risk and suggested women >35 on COC should consult their GPs about it. This was the only instance where a discussion was generated on the subject, with 2 of the 4 non COC-related stroke users commenting that insufficient warning was being given on stroke risk with COC.

This is a limited analysis, designed to give a sense of the potential of the methodology to yield self-initiated data from a hard to reach group. Of relevance here are: the fact there are no posts about CVD being misinterpreted, and patients' sense that it is important to mention stroke risk when COC is initiated, with no comment about whether this should be done quantitatively (through discussing percentages, e.g.) or qualitatively, despite research evidence favouring the former.¹

Reference

1. Neuner-Jehle S, Senn O, Wegwarth O, Rosemann T, Steurer J. How do family physicians communicate about cardiovascular risk? Frequencies and determinants of different communication formats. *BMC Fam Pract* 2011, **12**:15.