

19 THE DYNAMICS OF TRUST AND STRUCTURAL COERCION WITHIN A MENINGITIS TRIAL IN SUB-SAHARAN AFRICA

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Background Clinical trials in sub-Saharan Africa typically offer better medical care than is routinely available. This can lead to structural coercion where an individual may consent because of a lack of alternative options and potentially despite being uncertain about the research. An inherent component of this decision making process is an assessment of trust. Trust in the treatment options, the research team, and the process as a whole. This may be polarised in the context of life-threatening illnesses where recruitment (or not) could determine survival.

Aim We sought to understand the dynamics of trust and structural coercion in a multi-site clinical trial for HIV-associated cryptococcal meningitis.

Methods We embedded an ethnographic study within a clinical trial for HIV-associated cryptococcal meningitis. We conducted in-depth interviews with trial participants and their next-of-kin in Uganda and Botswana. We combined these with direct observations and in-depth interviews with researchers working at the African sites and European partner institutions. Interviews were transcribed, translated, and subject to narrative analysis.

Results To date we have recruited 14 trial participants, five next-of-kin and ten researchers. Recruitment is on-going until March 2021. Participants and their relatives often felt they had no choice but to enrol in the clinical trial which was their best chance of survival. Despite the perceived benefits of participation, recruitment came at a cost to participants who agreed to invasive medical procedures such as lumbar punctures despite pre-existing beliefs they could cause death. The severity of the illness contributed to poor comprehension of what the trial entailed and the decision to participate was heavily based on trust in the research team.

Conclusions Structural coercion is a significant factor impacting recruitment into clinical trials in resource-limited settings. In the context of life-threatening illness, trust superseded the need for an in-depth understanding of the research process.