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Article Title: Perceptions of oral cholera vaccine and reasons for full, partial and non-acceptance during a humanitarian crisis in South Sudan

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Key words: vaccine perceptions, cholera, oral cholera vaccination, vaccine acceptance, vaccine hesitancy, humanitarian crisis

Abstract (300 words max):

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Oral cholera vaccination (OCV) campaigns were conducted from February to April 2014 amongst internally displaced persons (IDPs) in the midst of a humanitarian crisis in Juba, South Sudan. IDPs were predominantly members of the Nuer ethnic group who had taken refuge in United Nations bases following the eruption of violence in December 2013. The OCV campaigns, which were conducted by United Nations and non-governmental organizations (NGOs) at the request of the Ministry of Health, reached an estimated 85% of the target population. As no previous studies on OCV acceptance have been conducted in the context of an on-going humanitarian crisis, semi-structured interviews were completed with 49 IDPs in the months after the campaigns to better understand perceptions of cholera and reasons for full, partial or non-acceptance of the OCV. Heightened fears of disease and political danger contributed to camp residents' perception of cholera as a serious illness and increased trust in United Nations and NGOs providing the vaccine to IDPs. Reasons for partial and nonacceptance of the vaccination included lack of time and fear of side effects, similar to reasons found in OCV campaigns in non-crisis settings. In addition, distrust in national institutions in a context of fears of ethnic persecution was an important reason for hesitancy and refusal. Other reasons included fear of taking the vaccine alongside other medication or with alcohol. The findings highlight the importance of considering the target populations' perceptions of institutions in the delivery of OCV interventions in humanitarian contexts. They also suggest a need for better communication about the vaccine, its side effects and interactions with other substances.

1. Introduction

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Cholera remains a significant public health problem in South Sudan where an ongoing political crisis has led to over half a million refugees and 1.5 million internally displaced persons (IDPs) (1). In 2010, WHO recommended that oral cholera vaccination (OCV) be used in conjunction with other cholera prevention and control measures (2). Three years later, 2013, a global OCV stockpile was created to improve access to the vaccine in event of outbreaks and humanitarian emergencies. Two United Nations bases in Juba became protection of civilian areas (PoC), housing over 30,000 IDPs, after the onset of violence in December 2013. An assessment indicated that PoC residents were at high risk of cholera given the density of population, inadequate water and sanitation facilities and imminent onset of seasonal rains. OCV campaigns were conducted in both PoCs following a request for stockpiled vaccines by the Ministry of Health (3). Cholera outbreaks are often associated with humanitarian emergencies but the use of OCV in humanitarian crises represents a new public health intervention. Only 7 countries have documented experiences with OCV campaigns and reasons influencing vaccine acceptance, three of which included humanitarian actors (4). In Guinea and Haiti, non-vaccination was mostly attributed to being absent during the time of the campaign (5, 6). The greatest barrier to OCV uptake in Tanzania was described as an extended absence from home because of competing obligations or priorities in relation to work, education or visiting relatives. This was followed by lack of information about the campaign, sickness and fear of possible side effects (7). OCV campaigns in Haiti, Guinea and Thailand, indicated a lower level of acceptance among adult men (5, 6). No studies of OCV acceptance have been conducted in the context of an on-going humanitarian crisis characterized by violence as found in South Sudan. This context presents unique circumstances with respect to the relationships between the affected population, and the national and international organizations governing access to care. This paper presents the results of an in-depth study of reasons for full, partial and non-acceptance of the OCV among IDPs in South Sudan.

2. Methodology

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2 Study Setting and Population

3 This study was set in two PoC sites (Tomping and UN House) in Juba, South Sudan. PoCs were 4 established as safe havens for people who sought protection in United Nation bases from the effects 5 of violence. Due to the ethnic nature of the conflict, these PoCs came to be predominantly occupied 6 by Nuer peoples. The security of PoCs is maintained by peacekeeping forces under the United Nation's 7 Mission in South Sudan (UNMISS), while health, food and education services are provided by various 8 non-governmental organizations (NGOs). Although the government of the Republic of South Sudan (RoSS) does not provide services in the PoCs, they serve a gatekeeping role by determining which 9 10 NGOs can operate in the country. 11 OCV vaccination campaigns were conducted among IDPs in both PoCs from February to April 2014. 12 Population estimates of Tomping and UN House at the time of the campaigns were 19,000 and 12,000, 13 respectively (3). The campaigns were pre-emptive as no cases of cholera had occurred in the PoCs 14 at the time of vaccination. The WHO pre-qualified OCV Shanchol was used, which has a two dose 15 regimen given two weeks apart for complete vaccination. In preparation for the campaign, PoC 16 residents were provided with health education messages on cholera, its prevention and treatment 17 and the planned vaccination campaign. OCVs were given to all >1year old who presented at 18 designated stations within each PoC, excluding pregnant women. Paper cards documenting the date 19 and dose of the vaccination were provided to all recipients. WHO estimates that 85 to 96% of the 20 target population in each PoC received one or two doses of OCV as based on self-reporting or evidence 21 from vaccination cards (3, 8). Complaints concerning the taste of the vaccine and physical symptoms 22 such as nausea, diarrhoea and stomach pains were reported (3). Turnout among men was lower than 23 that of women and children in both PoCs (3).

Study Design

This qualitative study took place four months after the OCV campaigns. Semi-structured interviews were conducted with adult residents of both PoCs. Respondents were purposively selected on the basis of their vaccination status: fully vaccinated (received both doses of the vaccine), partially vaccinated (received one dose) and refused vaccination (received no dose). Vaccine doses were validated by presentation of vaccine cards. Respondents were found by walking through different sections of the PoC and approaching people for interviews. Potential respondents were approached in their homes and told about the study. If they expressed interest in participation, then they were screened for eligibility and taken through the process of informed consent. Respondent selection also prioritized gender balance and those living with young children. PoC residents who were health workers (including health and hygiene promoters and medical assistants) were excluded from participation in the study. Interviews occurred in and around respondents' homes at times convenient for them and lasted between 30 and 45 minutes. Interviews were conducted by trained research assistants from the PoC populations in the Nuer language. All interviews were recorded and simultaneously translated and transcribed immediately after interviews. A subset of transcripts and recordings were given to research assistants from the other PoC to check for accuracy of translations. Informed consent was obtained in writing from each participant after the nature and possible consequences of the study had been fully explained.

Data Analysis

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Data analysis began during interviews with reviews and clarifications of transcripts with research assistants. Quotes were edited only as needed to improve readability while maintaining the structure and intention of the language. The results of discussion of cultural relevance of various phrases and ideas were documented with notes. Transcripts were then sorted in Nvivo 10. After a second reading of all transcripts, coding began under the main themes covered in the interview guide. Themes included perceptions of cholera, perceptions of the cholera vaccine and reasons for full, partial and

- 1 non-vaccination. A validation of coding structures took place through two open-coding seminar
- 2 sessions during which a subset of transcripts was shared with colleagues to generate and discuss
- 3 themes. This iterative process allowed for additional themes to emerge which were later reorganized
- 4 as sub-themes after additional reading of transcripts by DP.

Results

- 6 Characteristics of Respondents
- 7 A total of 49 interviews were conducted 25 from Tomping and 24 from UN House. All respondents
- 8 were Nuer who were 7-10 months into their residence in the PoCs. The average age of respondents
- 9 was 33 years (range 20 56 years). Less than half of the respondents had any primary schooling.
- 10 With the exception of one person, all respondents were from the immediate vicinity of Juba. All
- 11 respondents reported using the communal tap stands and latrines as their sole basis of hygiene
- 12 activity. Hand washing facilities with water and soap were observed in most homes.
- 13 Perceptions of Cholera
- 14 All respondents perceived cholera as a very serious illness. Cholera was consistently named along with
- 15 malaria, typhoid and HIV/AIDS as the worst illnesses facing residents. Although malaria was
- 16 considered the most common illness, cholera was considered the most serious. The word for cholera,
- 17 caamjiec kepitiboor, "diarrhoea which is white", evoked feelings of anxiety and fear because of the
- speed of illness onset and demise if not quickly treated.
- 19 Perceptions of cholera appeared to be influenced by philosophical and political associations of
- 20 causality. While some conceptualised cholera in matter of fact terms such as a recurring aspect of the
- 21 disease landscape and as God's will, others situated cholera within a larger discourse of injustice
- 22 related to the ongoing political context. For them, cholera was the result of being in the PoCs. And
- being in the PoCs was a result of the political crisis:

"If people will continue living in PoCs, as there is no peace, it will be a threat since cholera

comes as a result of poor hygiene and sanitation and high population of people in a small

area." (R48), 1 dose

Respondents were aware of their own ability to prevent cholera. The prevention behaviors described related to personal hygiene and environmental cleanliness, and included: drinking clean water, washing hands, washing utensils, food hygiene (keeping food covered) and "keeping [surroundings] clean." Latrine use was less frequently mentioned. Most descriptions of prevention behaviors were accompanied by the rationale of preventing flies, which were commonly discussed both as an indication of poor hygiene and as transmitters of cholera. The limitations of individual preventative behaviors within the PoC environment caused concern among some respondents. Several people referred to communal latrines, crowding and a lack of control over one's domestic environment as inescapable barriers to their prevention efforts:

"I can [protect] myself. I am sure for that, but children can still increase my chances of getting it. I make sure I wash my utensils and keep my environment clean but children if I am away will find their way to contaminate the utensils especially the cups for drinking." (R07), 2 doses

Perceptions of OCV and reasons for full vaccination

The OCV campaigns were positively perceived by all respondents. They described vaccination in terms of an individual decision to protect against cholera. Most felt less worried after receiving the vaccination although many reported feeling nauseous for up to two days afterwards. There was generally a high level of confidence that the vaccination campaign prevented a cholera outbreak within the PoCs. Many hoped to be vaccinated again and recommended the same to others.

Reasons for partial vaccination

23 Most respondents who were partially vaccinated received the first dose but missed the second.

Respondents gave a range of reasons for partial vaccination, including being busy, lack of awareness,

1 avoidance of discomfort and fear of combining the vaccine with other medication and alcohol. Being

2 busy at the time of the second dose was a common reason. Activities described as keeping people

3 busy included childcare, day labor or housework.

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4 All partially vaccinated respondents were aware of the need for two doses. Their awareness of other

factors such as knowing the timing of the second round and about contraindications around OCV were

less certain. Furthermore, awareness of the need for 2 doses did not preclude questioning the dosage

recommendation. Some simply felt they were adequately protected with one dose while others felt

that dosage needed to increase to 3 or 4, depending on body size:

"Yes, I refuse to take two doses because there is no difference from getting two or one. I been confused by people by saying you can take only one and [one] should be enough to protect you from getting cholera." (R45), 1 dose

Most respondents complained of the taste and smell of the vaccine, regardless of number of doses.

In more extreme instances this experience resulted in nausea and vomiting which led a person to

believe the vaccine could be spreading cholera:

"[after first dose] I felt nausea and I was worried may be it can contaminate me."(RO2), 1 dose

Alcohol consumption was often linked to partial vaccination and vaccine refusal but only among men.

In the case of partial vaccination, alcohol consumption was said to lead to feelings of illness when combined with the vaccine:

"Yes after vaccination [with the] first dose when I took different thing (alcohol), I feel dizzier and friends told me it is that vaccine you took. I suspended drinking for five days. After I get myself well, I resumed and joined my friends. So I fear to go for second dose. During second dose I increased the amount of alcohol and I was drunk and sleeping to avoid people reminding me to go for vaccination." (R29), 1 dose

- 1 One participant interviewed received only the second dose of OCV. Her story of rejecting the first
- 2 dose and accepting the second dose involved a process of overcoming distrust of the government in
- 3 favor of trust in the UN and her friends:

"Of course in the beginning I was about to refuse because of distress in [my] mind. I thought the government sent us a poison to kills us in UNMISS but later I realized the vaccine is from UN and the NGOs then I decided to take....I saw a lot of people going for it then even me I made a decision to go....I admitted some advice from people. No one can stay without being advised."(R27), 1 dose

Reasons for not getting vaccinated

Respondents who refused to be vaccinated generally described the severity, causes and prevention of cholera in the same way as those who were vaccinated. Their choice not to be vaccinated was described in terms of active decision making driven by reasons such as preference for drinking alcohol, preference for traditional medicine, distrust in the authenticity of the vaccines, and witnessing adverse reactions among those who had been vaccinated.

Both alcohol and traditional medicines were described as part of wider plan of resilience which had served people well thus far. One man described alcohol as one of the factors contributing to his personal invincibility as a soldier who had survived South Sudan's cycles of war dating back to 1956. Another man described the vaccine as being at odds with his preferred approach of using traditional medicine. But this preference was entangled with the issue of unreliable access to modern medicines such as vaccines:

"I use traditional medicine because sometimes you can go to where there is no medicine. When I was in the village, I use neem and other traditional trees that are very bitter and sour....God works on his own way. I acquainted myself [with] avoiding these modern medicines. That is why I did not take that vaccination." (R33), 0 doses

- 1 Those refusing OCV also cited issues of distrust as a reason. In this instance, lack of trust in the
- 2 authenticity of the vaccine came to the fore. Although the connection was not always explicit,
- 3 statements about distrust often accompanied references to national institutions, which were
- 4 commonly seen by PoC residents as persecutory:
- 5 "Yes because the drug they give are photocopies [fake]. If they are good medicines which
- 6 prevent or cure disease, I could go but some of medicine are fake so I like to die without getting
- 7 that medicine... Let me die here from cholera and HIV/AIDS....Why should I look for vaccination
- 8 that contaminated people?"(R35), 0 dose
- 9 For those who were partially vaccinated, the physical characteristics of OCV, smell and taste were
- 10 reported as the reasons for hesitancy. However, additional social influences such as witnessing or
- 11 hearing others talk about adverse reactions was sufficient to lead to vaccine refusal for one
- participant. Furthermore, it was not clear the extent to which some of these side effects might have
- been perceived as contracting cholera after being vaccinated. This perception led one man to
- 14 question the value of the vaccine altogether.
- 15 "Yes I have seen that the vaccine helps nothing because even those who took it got cholera.
- Then why I have to take it? I just [have] to protect myself by following the instructions [for]
- 17 prevention."(R40), 0 dose
- 18 Future of OCV and cholera control
- 19 Half of respondents had further questions about OCV. Their questions touched on specific facts about
- 20 the vaccine, such as its composition and duration of protection, and the possibility of further
- vaccination campaigns for future cholera outbreaks. When asked about the possibility of future
- 22 outbreaks, most said this was possible. They put responsibility for prevention on UN and NGOs
- working in the PoCs.

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3. Discussion and Conclusion

This study identified several reasons influencing full, partial and non-acceptance of OCV in a humanitarian crisis. The high level of acceptance of OCVs in this context can be attributed in part to perceptions of cholera as a severe disease evoking fear and perceptions of PoCs as places of increased risk of cholera. Perceptions of cholera risk extended beyond the domain of health to incorporate contextual circumstances of the political crisis which led to displacement into PoCs. In the context of ethnic conflict, explanations of cholera and cholera vaccine uptake drew upon a broader social and political narrative which constructed international organizations such as the United Nations and NGOs as protective intermediaries between the PoC populations and the government which many camp residents feared. Within this narrative, there was a high level of confidence in the OCV campaign and it was credited with the prevention of cholera outbreaks in both PoCs by residents. This confidence in and acceptance of OCV was not uniform, however. Some reasons for partial and non-acceptance of OCV such as lack of time and fear of side effects were consistent with reasons found in other settings and with reasons captured in WHO's vaccine coverage survey data from the PoCs (5-7). These reasons are increasingly important aspects of research on vaccination uptake as public perceptions have led to declines in rates of routine vaccination, and to barriers to the introduction of new vaccinations (9, 10). Trust in international organizations was an important aspect of vaccination decision-making in the Juba PoCs. A recent global review of attitudes towards vaccination found that mistrust in institutions often underpins the most common reasons for vaccine hesitancy (11). The nature of institutional trust in this context may be construed slightly differently however, since it worked in two directions—as a reason for hesitancy if the recommendations were perceived as coming from the government and a reason for acceptance if they were coming from the UN and NGOs. Alcohol consumption also recurred as a reason for partial and non-acceptance of OCV among men in the study. Fear of illness from combining the vaccine with alcohol and the perception of alcohol as a means for personal resilience affected decisions. The problem of alcohol abuse in conflict affected

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- 1 populations warrants further study since it relates to behaviours that lead to greater risk of cholera
- 2 and as a potential contributor to lower rates of vaccination among men (5, 6, 12).
- 3 Although most respondents described the decision to be vaccinated as an autonomous choice, social
- 4 influences also appear to have played a role in overcoming hesitancy in relation to distrust and
- 5 witnessing side-effects, and it was striking that most respondents reported recommending others to
- 6 be vaccinated. Further research should explore how to capitalise on social influence in this context.

Conclusion

- Although reasons for full, partial and non-acceptance of OCV among respondent POC populations in Juba largely mirrored the reasons for non-acceptance in non-crisis settings, some context-specific socio-political nuances also emerged in this setting affected by ethnic violence. Heightened fears of disease and political danger contributed to camp residents' perception of cholera as a serious illness and increased trust in those providing the vaccine. These were significant reasons for high (estimated 85%) acceptance of the OCV campaign in PoCs in Juba. These findings indicate the importance of monitoring and taking into account target population perceptions of service providers in planning the delivery of OCV interventions in humanitarian crises. Future OCV campaigns in crisis settings might also benefit from greater coverage by taking the role of alcohol into account and incorporating strategies to specifically target alcohol users in this target population. As in other settings, OCV campaigns in humanitarian contexts should not neglect the importance of communicating information about the vaccine dosage, expectations of side effects and interaction with other medication and alcohol consumption.
- There are two main limitations of this study. The first is the length of time between the vaccination campaign and the conduct of interviews was approximately four months. The potential impact of this time delay with regards to respondents' recall is not known. However, it is plausible that a degree of recall bias existed, with participants who were not vaccinated being more likely to recall negative perceptions or discussions about the vaccine than those who were vaccinated. The second limitation

- of this study are the limitations in generalizability. As a qualitative study, sampling was purposive and
- 2 not designed to be statistically representative. Further studies using statistically representative and
- 3 standardized sampling methods or more qualitative studies in different contexts are recommended
- 4 for purposes of generalizability.

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- 16 Author Contributions: DP led the study. JP, GJR, HL contributed to conceptualization of study and
- 17 tools development. AA, AC, SM and WP contributed to data collection. JP contributed to analysis of
- results. All authors contributed to the preparation of the manuscript.

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- affected populations? Addiction. 2015;110(6):889-90.

Table A: Vaccination Status of Study Respondents

		Tong Ping PoC	UN House PoC	Total
Study Respondents	Fully vaccinated	(8 males; 5 females)	(4 males; 2 females)	19
	Partially vaccinated	(3 males; 4 females)	(5 males; 6 females)	18
	Not vaccinated	(4 males; 1 female)	(5 males; 2 females)	12
	Totals	25	24	49