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## PROVIDER PERSPECTIVES OF THE IMPLEMENTATION OF DECENTRALISED CARE FOR DRUG RESISTANT TUBERCULOSIS PATIENTS IN SOUTH AFRICA: A QUALITATIVE STUDY

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4 **PROVIDER PERSPECTIVES OF THE IMPLEMENTATION OF DECENTRALISED CARE FOR DRUG RESISTANT**  
5 **TUBERCULOSIS PATIENTS IN SOUTH AFRICA: A QUALITATIVE STUDY**  
6

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## ABSTRACT

**Objectives:** Drug resistant tuberculosis (DR-TB) is a growing concern in many low-and middle-income countries. Facing rising numbers of DR-TB patients, South Africa introduced a decentralised model of care for DR-TB in 2011. We aimed to document the introduction and roll-out of new models of care for patients with DR-TB in 4 provinces (Northern Cape, KwaZulu-Natal, Eastern Cape and Gauteng) in 2015 using mixed methods, including interviews, register reviews and clinical audits. This paper reports on the qualitative component of the study.

**Design:** This is a qualitative interview study

**Setting:** Data were collected in 24 decentralised DR-TB sites, primary healthcare facilities and district hospitals.

**Participants:** 58 healthcare workers and facility staff in the above facilities were included in qualitative interviews.

**Results:** Healthcare workers felt communication and consultation about the new model of care was scarce to non-existent. This created resistance against the new model of care. They expressed a need for support from the district and province to guide them through the changes resulting from decentralised care, but this support was often lacking. Many respondents expressed feeling isolated and not supported by other healthcare providers.

**Conclusion:** Implementation of a new system of care in healthcare services can be difficult and does not always result in the intended outcomes. Improved communication and consultation with frontline providers and addressing fear and resistance that may be raised by changes in daily practices should be addressed to ensure successful implementation of the new model of care and prevent negative consequences that can hamper quality of care for patients. Attention should be paid to how support can be provided to frontline healthcare workers dealing with DR-TB.

### STRENGTHS AND LIMITATIONS OF THE STUDY

- This study provides new information about frontline healthcare workers' and facility staff experiences of decentralising DR-TB care in a high burden country.
- The study was conducted in 9 districts in four provinces, ensuring an adequate range of experiences from providers between provinces, as well as between rural and urban areas.
- The study provides insight into the perceptions and experiences of staff within different levels of care.
- However, as this is a qualitative study results cannot be generalized beyond the specific facilities that participated in the study.
- More research is needed to obtain a holistic picture of the effects of decentralising DR-TB on healthcare workers and patients.

## PROVIDER PERSPECTIVES OF THE IMPLEMENTATION OF DECENTRALISED CARE FOR DRUG RESISTANT TUBERCULOSIS PATIENTS IN SOUTH AFRICA: A QUALITATIVE STUDY

### BACKGROUND

Decentralisation has been a key health sector reform in most low and middle-income countries in the past two decades.(1) Decentralising responsibility for the management and provision of health care to local spheres of government aims to reduce inequalities, increase access, and improve services.(2) Facing rising numbers of drug resistant tuberculosis (DR-TB) patients and poor treatment outcomes, South Africa began to pilot decentralised models of care for DR-TB patients in 2008.(3) Tuberculosis (TB) still affects thousands of people around the world every day. Globally in 2017, an estimated 10 million people fell ill with TB while an estimated 1.3 million died from the disease.(4) In South Africa, TB remains the leading cause of death and drug resistance has increasingly become a major public health threat.(5) The move to pilot decentralisation of DR-TB care in South Africa followed studies in Peru and Vietnam conducted in the nineties that showed good results for ambulatory treatment among DR-TB patients.(6, 7) Subsequently, results of pilot studies in KwaZulu-Natal (KZN) and the Western Cape (WC) in South Africa showed that decentralised care was more effective than care in a central, specialised hospital and that home-based care further increased treatment success.(8-11)

Following these results and a recommendation by the WHO in 2011 that “patients with multidrug-resistant tuberculosis should be treated using mainly ambulatory care”,(12) the National Department of Health (NDOH) introduced a strategy for decentralisation and deinstitutionalisation of DR-TB treatment in 2011.(3) The strategy proposed ambulatory treatment for DR-TB patients in good condition and reducing the length of hospitalisation for those that require admission (deinstitutionalisation), and transferring responsibility for the care and treatment of DR-TB patients from a provincial centralised level to lower levels of the health system (decentralisation). Decentralised management of DR-TB patients was expected to accommodate patients by treating them closer to their homes, reduce transmission by shortening time to initiation, improve treatment adherence, and improve cost effectiveness by reducing lengthy hospital stays in specialised hospitals.(3) The roll-out of the new models of care started in 2011, albeit with different degrees of speed and coverage in the different provinces. Nonetheless, by October 2015, there were 578 initiating decentralised units, covering all 52 districts in South Africa.(13)

Implementation of a new system or mode of operation in an organization requires significant changes at different levels of the organisation. The management of this organizational change, however, can be a difficult process and in many cases does not work out as it was intended.(14) Implementation often fails because it is conceptualized as a simple set of operational steps that need to be taken and doesn't take into account the effect that change will have on employees or the way employees attempt to cope with these changes.(15) Managing the fears and resistance of employees is therefore essential when implementing change, but these are frequently not sufficiently considered.(16) Studies in Nepal, Uganda and Swaziland have looked at healthcare worker experiences of a decentralised drug sensitive TB programme and reported issues with communication between different levels of the TB programme and poor coordination with other services in a community-based tuberculosis programme, as well as understaffing, lack of capacity and insufficient knowledge.(17, 18) However, in South Africa no studies

thus far have reported on health care workers' (HCWs) experiences of the implementation of the new decentralised model of care for DR-TB and how they perceive it to affect the quality of care for patients. In order to address this gap in the literature, we interviewed healthcare workers and facility management of decentralized DR-TB units and Primary Healthcare Centres (PHC) in four provinces about their experiences of the introduction and implementation of the "new system".

This paper focuses particularly on experiences of healthcare workers and facility management with communication and support from (provincial and district) management structures, and coordination and integration with general healthcare facilities and their staff, during the early days of the decentralisation and deinstitutionalisation, and how this influenced the quality of care provided to DR-TB patients.

## METHODS

### Context

In 2017, an estimated 322 000 South Africans fell ill with TB of which close to 16 000 cases were confirmed to have drug resistant TB.<sup>(4)</sup> While South Africa has made great strides to increase treatment success for drug sensitive TB to 82%, treatment success for DR-TB remains low at 55% with an average death rate of 22% and loss to follow up (LTFU) of 17%.<sup>(4)</sup>

Under the decentralised model of care for DR-TB in South Africa, decentralised DR-TB units are responsible for initiation and monitoring of treatment for drug resistant TB patients, while the provincial Centre of Excellence (centralised DR-TB unit) is responsible for initiation and monitoring of treatment for extensively drug resistant TB (XDR-TB) patients, paediatric patients, and patients with complications. The decentralisation of DR-TB services is paired with deinstitutionalisation whereby smear negative patients in fair to good general condition no longer need to be hospitalised and can be started on ambulatory treatment. This way, newly diagnosed patients no longer have to wait for a bed to become available and can instead immediately be initiated on treatment. Following initiation at the decentralised unit, patients are referred to their nearest primary healthcare facility (PHC) for daily observed treatment (DOT), daily injections, monitoring of side-effects and adherence via monthly sputums and routine tests, and tracing of treatment interrupters.<sup>(3)</sup>

While decentralised DR-TB units are mostly responsible for diagnosis and initiation on treatment, they often do not have the capacity or equipment to monitor side-effects and drug resistance, perform radiography to diagnose TB or audiology to monitor hearing loss, or provide transport, and therefore need the support from PHC facilities, general district hospitals and other general healthcare services like Emergency Medical Services (EMS). In addition, DR-TB patients often also suffer from other conditions like diabetes, HIV, cancer which cannot be treated at the DR-TB unit and needs involvement from general health services. PHC facilities and general hospitals are therefore expected to play a significant role in the decentralised model of DR-TB care.<sup>(3)</sup>

At the time of the interviews, implementation of the policy guidelines varied among provinces. In the Western Cape (WC), all PHC facilities offered treatment initiation, DOT and monitoring of treatment.

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2  
3 KwaZulu-Natal, Eastern Cape and Gauteng had fewer treatment initiation units and maintain semi-  
4 centralisation of clinical services.(13) DR-TB patients in these provinces were initiated at decentralised  
5 DR-TB units but then referred to PHC facilities for daily injections, DOT and monitoring of sputum. On a  
6 monthly or bi-monthly basis, patients returned to the decentralised unit for review of their treatment  
7 based on the results of the monthly sputum monitoring at the PHC facility. The Northern Cape was  
8 providing DR-TB services mainly through an outreach model while preparing PHC facilities to start  
9 initiating patients.  
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### 12 13 **Data collection and analysis**

14  
15 We conducted a cross-sectional exploratory qualitative study in the Eastern Cape, KwaZulu-Natal,  
16 Northern Cape and Gauteng. Ten decentralised units, one central specialized unit and 12 primary  
17 healthcare facilities were selected in agreement with provincial TB coordinators for data collection in  
18 these four provinces. Qualitative data were collected during multiple visits to each facility between  
19 November 2015 and April 2017. Purposive sampling was used to recruit 43 healthcare workers, based on  
20 their designation (primarily doctors and nurses) and placement (TB focal point), five administrative staff  
21 and two social workers. In addition, nine operational managers and five provincial/district TB coordinators  
22 were interviewed to allow for a wide range of perspectives and contextualisation.  
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27 A semi-structured interview guide was developed for each type of staff category (nurse, doctor,  
28 operational manager, district TB coordinator) with questions relating to their knowledge and training,  
29 tasks, personal perceptions, challenges, support and resources. Questions were open-ended and the  
30 interviewer led the interview as little as possible to make participants feel more comfortable in sharing  
31 their personal perceptions and experiences.  
32  
33

34  
35 Transcripts and notes were coded and analysed using thematic content analysis (19). Transcripts were  
36 read and re-read to allow for familiarisation and to start the process of open coding. Coding was  
37 performed inductively, without following predetermined codes. Codes were grouped into clusters around  
38 similar and interrelated ideas from which several themes emerged.  
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### 41 **Patient and Public Involvement**

42  
43 We did not involve patients or the public in this work.  
44

### 45 **Ethical considerations**

46  
47 The study was approved by the Ethics Committee of the South African Medical Research Council (EC023-  
48 8-2015). All participants were given informed consent forms which were read together with the  
49 participant and explained in detail before being signed. Participants were informed about the purpose of  
50 the study, procedures involved, risks and benefits of the study, and their rights as participants. The right  
51 to decline participation was emphasised, as well as an assurance given that the decision not to participate  
52 would not affect their work or relationship with superiors, colleagues and patients. Participants were  
53 given an assurance of confidentiality and strict protection of collected data. Most interviews were  
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3 recorded and transcribed. Some participants however did not feel comfortable being recorded. During  
4 these interviews, notes were taken.  
5

## 6 7 **RESULTS**

8  
9 Between November 2015 and April 2017, 67 interviews were conducted with 43 healthcare workers  
10 (HCWs), five administrative staff, two social workers, nine operational managers and five  
11 provincial/district TB coordinators at ten decentralised units, one central specialized unit and 12 primary  
12 healthcare facilities in four provinces in South Africa: Eastern Cape (EC), KwaZulu-Natal (KZN), Gauteng  
13 (GP) and Northern Cape (NC). For the purpose of this article and its focus on experiences of HCWs and  
14 facility management of the implementation of a new system, we excluded the interviews with  
15 administrative staff, social workers and TB coordinators as these had a different focus, therefore in the  
16 analysis we had a total of 58 interviews. (Table 1)  
17  
18

19  
20 Several themes emerged from the interviews relating to operational challenges, communication and  
21 support, leadership, training, human resources, infection control and infrastructure, and finances and  
22 resources. For this manuscript, however, we focused on those related to communication and support, as  
23 these came up strongly in the data, and raised several implications for effective patient care.  
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26 Table 1: Details of interviews  
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Province	Facility type	Staff category	Number of participants (F/M)	Number of interviews
Eastern Cape	Decentralised unit	Nurse	3/0	4
	Decentralised unit	Doctor	2/1	3
	Decentralised unit	Manager/Chief Executive Officer	1/1	2
	Primary Healthcare Clinic	Nurse	7/0	7
	Primary Healthcare Clinic	Manager/ Chief Executive Officer	0/1	1
	<b>Total Eastern Cape</b>		<b>16</b>	<b>17</b>
	KwaZulu-Natal	Decentralised unit	Nurse	2/0
Decentralised unit		Doctor	1/1	2
Decentralised unit		Manager/ Chief Executive Officer	1/1	2
<b>Total KwaZulu-Natal</b>		<b>6</b>	<b>6</b>	
Gauteng		Decentralised unit	Nurse	5/0
	Decentralised unit	Manager/ Chief Executive Officer	3/0	3
	Primary Healthcare Clinic	Nurse	7/1	9
	<b>Total Gauteng</b>		<b>16</b>	<b>21</b>
Northern Cape	central unit	Nurse	2/0	2
	central unit	Doctors	1/1	2
	Decentralised unit	Nurse	3/0	3
	Primary Healthcare Clinic	Nurse	6/0	6
	Primary Healthcare Clinic	Manager/ Chief Executive Officer	0/1	1
	<b>Total Northern Cape</b>		<b>14</b>	<b>14</b>
	<b>TOTAL</b>		<b>52</b>	<b>58</b>

Three main themes relating to communication and support emerged from the analysis:

- 1) Consultation and communicating decentralisation: “they just dropped it on us”
- 2) Support from district and province: “Do you think they care – but we must deliver”
- 3) Inadequate coordination and integration between the DR-TB programme and general healthcare services: “Once we refer them back, we lose control of them”.

### 1) Consultation and communicating decentralisation: “they just dropped it on us”

Healthcare workers in all four study provinces remarked that communication and consultation had been scarce to non-existent. In most facilities treatment and care for DR-TB patients was simply added to the workload of the TB (and/or HIV) room.

*Like I said they just dropped it on us, without no explanation, the one moment I had nothing the next moment I have eight patients. (Nurse, PHC, Gauteng)*

Many healthcare workers felt that these decisions were taken over their heads, even though it affected their daily work and their own personal health, creating anxiety and tension among healthcare workers.

*What happens is that, like when we are attending a workshop or meeting. They just talk about it, but really we don't know what is happening with this decentralisation. In the papers it is stated that it is a satellite, but us as a TB focal, we don't know anything. (Nurse, decentralised unit, Gauteng)*

Especially in the Eastern Cape, a rural province, healthcare workers at PHC facilities were agitated about the manner in which decisions were made. While most HCWs at decentralized DR-TB units mentioned previous experience with drug-resistant TB patients, the majority of HCWs at primary healthcare level did not have this experience and expressed concern with the sudden addition of DR-TB patients to their daily routine.

As one healthcare worker remarked:

*It was forced upon us. We're afraid of initiating DR (-TB treatment) because of the side-effects. How to manage all this? We had a quick training but nobody walks you through it on the job. Then something goes wrong and people litigate against the department and the nurse is held responsible. (Nurse, PHC, EC)*

Several of the PHC clinics in the EC where HCWs were agitated about the decision to decentralise DR-TB to PHC level, experienced challenges including frequent loss to follow up of patients, lack of records, and critical patients being referred to the DR-TB unit without stabilising the patients before transfer, which resulted in the death of the patient.

*Clinic X gives major problems with referral. In the last few months they transferred 3 critically ill patients to the decentralised DR-TB unit that died on arrival. (Nurse, decentralised unit, Eastern Cape)*

### 2) Support from district and province: “Do you think they care – but we must deliver”

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3 At a district level, the implementation of decentralisation was the responsibility of the district TB  
4 coordinator. He/she is responsible for informing, training and supporting the decentralised DR-TB units  
5 and PHC facilities that are providing DR-TB care. Healthcare workers in the TB room particularly felt that  
6 they needed the support from the TB coordinator to guide them through the changes, to monitor that  
7 they are doing it right, and to assist them with logistical and patient-related challenges. Most healthcare  
8 workers and facility managers, however, mentioned a lack of support from the district.  
9

10  
11  
12 *The challenges that we have is when the district coordinator, I don't know whether it's a sub district*  
13 *coordinator or the district coordinator. She does not come to visit us. She doesn't come to support us. She*  
14 *doesn't at all. So now we end up not knowing whether we are right or we are wrong you understand?*  
15 *(Nurse, decentralised unit, Gauteng)*  
16

17  
18 While participants commended the provincial department of health for supporting the facilities with  
19 equipment such as the Kudu Wave (portable audiometer) and laptops, and providing training for DR-TB,  
20 continuous support and presence from the province also seemed to be lacking.  
21

22  
23 *Provincial people come down here with a book and write down challenges but we never hear from them*  
24 *again. (Nurse, decentralised unit, EC)*  
25

26  
27 *They don't care about us. Do you think they care? But we must deliver. (CEO, decentralised unit, EC)*  
28

29 District support, however, seemed to be related to a lack of capacity. In one district the post for TB  
30 coordinator could not be filled due to a moratorium on appointments.  
31

32  
33 *I can't say there's any support from the district. There's no TB coordinator in the district. They had one but*  
34 *the post is open again. Even the HAST manager, I haven't seen here. I've never seen or heard anything or*  
35 *had any support from the district. The problem, I think, is that they have no deputy director for TB. You*  
36 *can't expect the district manager to visit all the institutions. They were supposed to make sure that they*  
37 *fill the post for TB. (CEO, decentralised unit, EC)*  
38

39  
40 **3) Inadequate coordination and integration between the DR-TB programme and general**  
41 **healthcare services: "Once we refer them back, we lose control of them".**  
42

43 Healthcare workers at most decentralised units experienced problems with the surrounding PHC facilities.  
44 Once patients are down referred to PHC facilities, patients need to be monitored by taking monthly  
45 sputum samples from patients to determine if the patient is responding to treatment. This was however  
46 seldom done, according to healthcare workers at the decentralised units.  
47

48  
49 *Once we refer them back to PHC, we lose control of them. (CEO, decentralised unit, EC)*  
50

51  
52 *Basic things need to be available. The absence of the monthly sputums is a huge challenge. ... So sometimes*  
53 *you sit in OPD having to review a patient with a gap of two three months of no sputum. ... At the end of it*  
54 *all you are not doing justice to the patient because you are making decisions without the correct*  
55 *information. (Doctor, decentralised unit, EC)*  
56

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3 In addition, healthcare workers at decentralised units complained of the refusal of PHC facilities to  
4 stabilise DR-TB patients before transferring them to the decentralised DR-TB unit.  
5

6  
7 *Patients are being referred here that are critically ill and not stabilized before transferring at the referring  
8 clinic. (Nurse, decentralised unit, EC)*  
9

10  
11 *They are rushing; won't see the renal problem, they won't see jaundice in that patient, they won't see  
12 hypertension and diabetes in that patient, they won't see cancer, they won't see anything – the lump that  
13 needs to be scanned or whatever. They would send– quickly rush that patient to us, to get rid of it. (CEO,  
14 decentralised unit, EC)*  
15

16  
17 The policy framework states that the existing TB nurses will be trained to handle these activities and PHC  
18 facilities will be supported by the nearest decentralised DR-TB unit or the provincial Centre of Excellence,  
19 and the district TB coordinators. Healthcare workers at PHC facilities and at decentralised DR-TB units,  
20 however, painted a picture of little support and too much work for nurses in PHC facilities.  
21

22  
23 *There's too much for the clinic sisters to do. They are making it practical for themselves to make it work.  
24 The sister is doing TB, child immunization, PMTCT, ARV. There's way too much for those sisters to cope at  
25 the clinic. How can this be resolved? More personnel. (Doctor, decentralised unit, EC)*  
26

27  
28 Difficulties with cooperation and coordination, however, were not limited to PHC facilities. Healthcare  
29 workers at decentralised DR-TB units spoke of serious difficulties with hospitals and general services when  
30 requesting services that they could not provide themselves but were essential to the well-being of the  
31 patient such as radiology, audiology and transport.  
32

33  
34 *You can make appointments make appointments and make appointments, but transport won't pitch  
35 because ambulance people are refusing to transport DR patients. Even with their masks on, I told them the  
36 other day 'don't worry about those that are diagnosed, worry about the other people that aren't diagnosed  
37 that you are transporting every day'. (Nurse, PHC, Northern Cape)*  
38

39  
40 *We send people to Hospital A for X-rays because we don't have a radiographer. But the radiographers  
41 there don't want to touch the patient because they are afraid of DR-TB. (CEO, decentralised unit, EC)*  
42

43  
44 Patients being injected with Kanamycin as part of their treatment regimen need to undergo a hearing test  
45 on a monthly basis to monitor any hearing loss due to the ototoxic effect of Kanamycin. Several HCWs at  
46 decentralised units, however, reported challenges accessing audiology services, resulting in patients  
47 suffering hearing loss.  
48

49  
50 *It's a problem because there is no baseline and patients tend to report at a much advanced state. .... By  
51 the time they come back for the review they are completely deaf or are at a stage where it's so advanced  
52 that it's irreversible. (Doctor, decentralised unit, EC)*  
53

54  
55 In the experience of staff at the decentralized units, many of these difficulties arise from fear and stigma  
56 of DR-TB with service providers that haven't received training for TB.  
57

1  
2  
3 *These doctors are scared of TB patients and refer them quickly. It's a problem with staff on that side. It's*  
4 *stigma of MDR and TB. They dump the patient here after hours when doctors and staff are off. (Nurse,*  
5 *decentralised unit, EC)*  
6

7  
8 *The attitude towards TB doesn't help. If a patient is admitted in casualty at the general hospital for a*  
9 *broken femur. But when he is a DR patient, they will leave everything and refer the patient immediately to*  
10 *TB hospital X. A lot of education needs to happen. (TB manager, Northern Cape)*  
11

## 12 13 **DISCUSSION**

14  
15 We reported experiences from healthcare workers and facility management of the introduction and  
16 implementation of the “new decentralised model of care for DR-TB”. We focused on experiences relating  
17 to communication and support, and coordination and integration, as these were the strongest themes in  
18 the data.  
19

20  
21 A fundamental but often overlooked difficulty in ‘change management’ is the ‘human factor’, managing  
22 the impact that change has on employees.(15) Fear of the unknown and uncertainty are often sources of  
23 resistance. People need predictability, which has to do with their basic need for security.(20) Many  
24 healthcare workers and facility managers in our study, however, felt that decisions were taken over their  
25 head even though it affected their daily work and their own personal health. Especially among HCWs in  
26 primary healthcare facilities that did not have previous experience or training in treatment of DR-TB, the  
27 introduction of DR-TB services at the facility created anxiety and tension, resulting in resistance against  
28 the new model of care and sub-standard quality of care. Several studies in South Africa have shown that  
29 when healthcare workers are not engaged with the development and implementation of a new policy,  
30 resistance can affect the quality of the services they offer.(1, 21, 22) For example, the lack of consultation  
31 with nurses whose daily practices were to be affected significantly when free healthcare was introduced,  
32 resulted in nurses rationing services as a coping mechanism.(22)  
33

34  
35 The need for information and consultation is even more essential when the new policy concerns a value  
36 laden or stigmatised condition, as for example found with the implementation of a new policy to increase  
37 access to safe abortions where healthcare workers outright refused to offer the service.(1) Similarly, in  
38 our study, the introduction of services for DR-TB, an infectious and deadly disease, raised anxiety on both  
39 a personal level i.e. the fear of infection, and on a professional level i.e. the frustration of an increased  
40 workload, and resulted in resistance to the new model of care. The PHC facilities where HCWs expressed  
41 the most concerns about the addition of DR-TB patients to their workload without their consultation were  
42 reported to face serious challenges with the management of DR-TB patients, such as frequent loss to  
43 follow up of patients, lack of records, and critical patients being referred to the DR-TB unit without  
44 stabilising the patients before transfer.  
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51 To reduce resistance, the future users of a system should be involved in the early phases of the project to  
52 create a sense of ownership.(23) Employees need to be a part of the process and they need to be heard,  
53 since people are more likely to accept the forthcoming change if they know what to expect.(16) Improved  
54 communication and consultation with frontline providers, and addressing the fear and resistance that is  
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3 evoked not only by the disease but also by the sudden change in daily practice, is therefore critical to  
4 ensure successful implementation of the new policy and prevent unintended negative consequences that  
5 can hamper quality of care for patients.  
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7

8 In addition to the lack of communication and consultation on the new policy, healthcare workers in our  
9 study also experienced isolation and a lack of support from other healthcare providers due to a lack of  
10 coordination and integration of the DR-TB programme with general healthcare services. Patients with DS-  
11 TB or DR-TB often suffer from several other acute and chronic conditions and are at a high risk of side-  
12 effects for which they require close monitoring and treatment.(3) Most DR-TB units in our study, however,  
13 were not equipped to monitor and treat a multitude of conditions and therefore relied on the services of  
14 primary healthcare clinics, general hospitals and other services like transport. When these services were  
15 refused, the DR-TB units had no mechanisms to remedy this situation. Several studies have reported on  
16 similar problems with referrals between different facilities, resulting in a lack of continuity of care, and  
17 negative consequences for patients.(24-26). These studies, however, date from before the  
18 implementation of decentralisation of DR-TB care. While decentralisation inherently requires strong  
19 coordination and effective referral between facilities to ensure continuum of care, our study shows that  
20 many of the problems with referral that were already reported before the implementation of  
21 decentralisation continued and might have worsened post-decentralisation. Insufficient integration of  
22 DR-TB services into existing TB, PHC and other general healthcare services and the resulting experiences  
23 of isolation and a lack of support from these services has been previously shown to affect treatment  
24 outcomes.(27)  
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31 The decentralisation of DR-TB has established a vertical programme with targeted delivery, and its own  
32 coordination, financing, information mechanisms, and lines of accountability. This vertical programme  
33 however has to function in an already established general district health system (DHS) which is not  
34 accountable to the DR-TB programme. As a result, as shown in our study, healthcare workers in the DR-  
35 TB programme found themselves in a position where they depended on the district health services to  
36 provide effective care to their patients but in many cases were at the mercy of these services and their  
37 willingness to assist. While much has been said and done about the integration of the HIV programme  
38 with the TB programme,(28, 29) and within the DHS,(30, 31) far less attention has been given to the  
39 integration of the DR-TB programme within the DHS. This lack of integration impacts on patient care,  
40 treatment outcomes, and patients' long-term quality of life. Coordination across care levels, and vertical  
41 and horizontal integration have been studied in the South African context, but mainly in the context of  
42 HIV. More research is needed to assess coordination and integration of DR-TB care, its effect on patient  
43 care and mechanisms to improve it.  
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49 Like all qualitative studies, these results cannot be generalized beyond the specific facilities that  
50 participated in the study though theoretical generalization to similar contexts and issues can be made.  
51 Our study mainly focused on decentralised DR-TB units and less on PHC and other general healthcare  
52 facilities. As a consequence, our results show the point of view of healthcare workers in decentralised  
53 units and have to a minimal degree incorporated experiences from other healthcare facilities. In no way,  
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3 however, does this study intend to cast blame on PHC and general healthcare facilities but recommends  
4 more research to obtain a holistic picture of the effects of decentralising DR-TB.  
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## 6 7 **CONCLUSION**

8  
9 Frontline healthcare workers are key in the Implementation of a new policy such as the decentralisation  
10 of DR-TB. While this new model of care affects their daily work and personal health, healthcare workers  
11 in our study reported a lack of consultation and communication regarding the implementation of the new  
12 model of care and feelings of isolation and a lack of support affecting the quality of care they provide.  
13

14  
15 Improved communication and consultation with frontline providers, and addressing the fear and  
16 resistance that is evoked not only by the disease but also by the sudden change in daily practice, are  
17 critical to ensure successful implementation of the new policy and prevent unintended negative  
18 consequences that can hamper quality of care for patients. In addition, improved coordination and  
19 integration of the DR-TB programme into the district health system can increase the levels of support  
20 needed by healthcare workers in the care of DR-TB patients and thereby improve the quality of care in a  
21 decentralised model of care.  
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23

## 24 25 **CONTRIBUTORSHIP**

26  
27 Dr Loveday conceptualised and was the Principal Investigator (PI) on the study “Monitoring the roll-out of  
28 new models of care for MDR-TB patients in South Africa” which provided the data for this manuscript.  
29

30  
31 Ms Lieve Vanleeuw and Ms Vuyelwa Mehlomakulu conducted interviews and collected data for  
32 aforementioned study. Ms Vanleeuw analysed the data and drafted the manuscript.  
33

34  
35 Dr Zembe-Mkabile and Associate Professor Atkins, together with Dr Loveday, reviewed and edited the  
36 manuscript multiple times and provided guidance to Ms Vanleeuw.  
37

## 38 39 **COMPETING INTERESTS**

40  
41 None declared.

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48 in the writing of the report; or in the decision to submit the paper for publication. All researchers were  
49 independent of funders and sponsors.  
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## 51 52 **DATA AVAILABILITY STATEMENT**

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## Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

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### Title and abstract

<p><b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	<p>Page 1, 4</p>
<p><b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>Page 2</p>

### Introduction

<p><b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>Page 4, 5</p>
<p><b>Purpose or research question</b> - Purpose of the study and specific objectives or questions</p>	<p>Page 4, 5</p>

### Methods

<p><b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	<p>Page 6</p>
<p><b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	<p>Page 6</p>
<p><b>Context</b> - Setting/site and salient contextual factors; rationale**</p>	<p>Page 6</p>
<p><b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	<p>Page 6</p>
<p><b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	<p>Page 6</p>
<p><b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	<p>Page 6</p>

1 2 3 4 5	<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 6
6 7 8	<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 7, 8
9 10 11 12	<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 6
13 14 15 16	<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 6
17 18 19 20	<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 6

## Results/findings

23 24 25 26	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 7-12
27 28 29	<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 7-12

## Discussion

32 33 34 35 36 37 38	<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 12-14
39	<b>Limitations</b> - Trustworthiness and limitations of findings	Page 13

## Other

42 43 44	<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 14
45 46	<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 14

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

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# BMJ Open

## PROVIDER PERSPECTIVES OF THE INTRODUCTION AND IMPLEMENTATION OF CARE FOR DRUG RESISTANT TUBERCULOSIS PATIENTS IN DISTRICT LEVEL FACILITIES IN SOUTH AFRICA: A QUALITATIVE STUDY

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4 **PROVIDER PERSPECTIVES OF THE INTRODUCTION AND IMPLEMENTATION OF CARE FOR DRUG**  
5 **RESISTANT TUBERCULOSIS PATIENTS IN DISTRICT LEVEL FACILITIES IN SOUTH AFRICA: A QUALITATIVE**  
6 **STUDY**  
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## ABSTRACT

**Objectives:** Drug resistant tuberculosis (DR-TB) is a growing concern in many low-and middle-income countries. Facing rising numbers of DR-TB patients, South Africa introduced a decentralised model of care for DR-TB in 2011. We aimed to document the introduction and implementation of the new models of care for patients with DR-TB in 4 provinces (Northern Cape, KwaZulu-Natal, Eastern Cape and Gauteng) in 2015 using mixed methods, including interviews, register reviews and clinical audits. This paper reports on the qualitative component of the study.

**Design:** This is a qualitative interview study

**Setting:** Data were collected in 22 decentralised DR-TB sites, primary healthcare facilities and district hospitals, and one provincial central DR-TB hospital.

**Participants:** 57 healthcare workers, facility staff and provincial and district TB coordinators were included in qualitative interviews.

**Results:** Healthcare workers felt that the introduction of DR-TB care in their facility came with little warning or engagement, creating fear and anxiety. They expressed a need for support from the district and province to guide them through the changes but this support was often lacking. In addition, many respondents expressed feeling isolated and not supported by other healthcare providers which they feel impacts on the quality of the care they provide.

**Conclusion:** Introduction of a new service such as DR-TB care can be difficult and does not always result in the intended outcomes. Improved engagement with frontline providers and addressing the fear and anxiety that may be raised by changes in daily practices should be addressed to ensure successful implementation and prevent negative consequences that can hamper quality of care for patients. Attention should be paid to how the decentralised DR-TB unit can be supported by district management and other healthcare providers.

## STRENGTHS AND LIMITATIONS OF THE STUDY

- This study provides new information about frontline healthcare workers' and facility staff experiences of the introduction and implementation of new models of care for DR-TB patients on a decentralized level in a high burden country.
- The study was conducted in 9 districts in four provinces, ensuring an adequate range of experiences from providers between provinces, as well as between rural and urban areas.
- The study provides insight into the perceptions and experiences of staff within different levels of care, as well as provincial and district management
- However, as this is a qualitative study results cannot be generalized beyond the specific facilities that participated in the study.
- More research is needed to obtain a holistic picture of the effects of decentralising DR-TB on healthcare workers and patients.

## PROVIDER PERSPECTIVES OF THE INTRODUCTION AND IMPLEMENTATION OF CARE FOR DRUG RESISTANT TUBERCULOSIS PATIENTS IN DISTRICT LEVEL FACILITIES IN SOUTH AFRICA: A QUALITATIVE STUDY

### BACKGROUND

Decentralisation has been a key health sector reform in most low and middle-income countries in the past two decades.(1) Decentralising responsibility for the management and provision of health care to local spheres of government aims to reduce inequalities, increase access, and improve services.(2)

Tuberculosis (TB) still affects thousands of people around the world every day. Globally in 2017, an estimated 10 million people fell ill with TB while an estimated 1.3 million died from the disease.(3) In South Africa, TB remains the leading cause of death and drug resistance has increasingly become a major public health threat.(4) Facing rising numbers of drug resistant tuberculosis (DR-TB) patients and poor treatment outcomes, South Africa began to pilot decentralised and ambulatory models of care for DR-TB patients in 2008.(5) The move to pilot decentralisation and deinstitutionalisation of DR-TB care in South Africa followed studies in Peru and Vietnam conducted in the nineties that showed good results for ambulatory treatment among DR-TB patients.(6, 7) Subsequently, results of pilot studies in KwaZulu-Natal (KZN) and the Western Cape (WC) in South Africa showed that decentralised care was more effective than care in a central, specialised hospital and that home-based care further increased treatment success.(8-11)

Following these results and a recommendation by the WHO in 2011,(12) the National Department of Health (NDOH) introduced a strategy for decentralisation and deinstitutionalisation of DR-TB treatment.(3) The strategy proposed ambulatory treatment for DR-TB patients in good condition and reducing the length of hospitalisation for those that require admission (deinstitutionalisation), and transferring responsibility for the care and treatment of DR-TB patients from a provincial centralised level to lower (district and local) levels of the health system (decentralisation). Decentralised management of DR-TB patients was expected to accommodate patients by treating them closer to their homes, reduce transmission by shortening time to initiation, improve treatment adherence, and improve cost effectiveness by reducing lengthy hospital stays in specialised hospitals.(3) The roll-out of the new models of care started in 2011, albeit with different degrees of speed and coverage in the different provinces. Nonetheless, by October 2015, there were 578 initiating decentralised units, covering all 52 districts in South Africa.(13)

Implementation of a new service or system in an organisation requires significant changes at different levels of the organisation. The management of this organisational change, however, can be a difficult process and in many cases does not work out as it was intended,(14) affecting the end user of the system or in the case of healthcare services the patients. Studies in Nepal, Uganda and Swaziland have looked at healthcare worker experiences of community based drug sensitive TB (DS-TB) programmes and reported issues with communication between different levels of the TB programme and poor coordination with other services in a community-based tuberculosis programme, as well as understaffing, lack of capacity and insufficient knowledge.(15, 16)

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3 While DS-TB is fairly easy to treat and has high treatment success rates, DR-TB is much more difficult to  
4 treat, has high mortality rates and its treatment has severe side-effects. As such, challenges with the  
5 introduction of DR-TB care at decentralised level, as well as the consequences for patient care might differ  
6 substantially to those from decentralisation of DS-TB. No studies thus far have reported on healthcare  
7 workers' (HCWs) experiences of the introduction and implementation of DR-TB, a more difficult to treat  
8 and deadlier disease than DS-TB, at district and local facilities and how they perceive it to affect the quality  
9 of care for patients. In order to address this gap in the literature, we interviewed healthcare workers and  
10 facility management of decentralized DR-TB units and Primary Healthcare Centres (PHC) in four provinces,  
11 as well as provincial and district TB coordinators about their experiences of the introduction and  
12 implementation of DR-TB care, following from deinstitutionalisation and decentralization, in facilities at  
13 district level, as well as how they perceive issues with the implementation to affect the care provided to  
14 patients. Issues explored included support from provincial and district management structures and the  
15 programmes coordination and integration with general healthcare facilities and their staff.  
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## 21 **METHODS**

### 22 **Context**

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24  
25 In 2017, an estimated 322 000 South Africans fell ill with TB of which close to 16 000 cases were confirmed  
26 to have drug resistant TB.(4) While South Africa has made great strides to increase treatment success for  
27 drug sensitive TB to 82%, treatment success for DR-TB remains low at 55% with an average death rate of  
28 22% and loss to follow up (LTFU) of 17%.(4)  
29  
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31 Under the decentralised model of care for DR-TB in South Africa, DR-TB units on district level are  
32 responsible for initiation and monitoring of treatment for drug resistant TB patients, while the provincial  
33 Centre of Excellence (centralised DR-TB unit) is responsible for initiation and monitoring of treatment for  
34 extensively drug resistant TB (XDR-TB) patients, paediatric patients, and patients with  
35 complications.(Figure 1) The decentralisation of DR-TB services is paired with deinstitutionalisation  
36 whereby smear negative patients in fair to good general condition no longer need to be hospitalised and  
37 can be started on ambulatory treatment. Following initiation at the decentralised unit, patients are  
38 referred to their nearest primary healthcare facility (PHC) for daily observed treatment (DOT), daily  
39 injections, monitoring of side-effects and adherence via monthly sputums and routine tests.(3)  
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44 Figure 1: Units for the decentralised management of DR-TB.(3)  
45

46 While decentralised DR-TB units are mostly responsible for diagnosis and initiation on treatment, they  
47 often do not have the capacity or equipment to monitor side-effects and drug resistance, perform  
48 radiography to diagnose TB or audiology to monitor hearing loss, or provide transport, and therefore need  
49 the support from PHC facilities, general district hospitals and other general healthcare services like  
50 Emergency Medical Services (EMS). In addition, DR-TB patients often also suffer from other conditions  
51 like diabetes, HIV, cancer which cannot be treated at the DR-TB unit and needs involvement from general  
52 healthcare services. PHC facilities and general hospitals are therefore expected to play a significant role  
53 in the decentralised model of DR-TB care.(3)  
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3 At the time of the interviews, implementation of the policy guidelines varied among provinces. In the  
4 Western Cape, all PHC facilities offered treatment initiation, DOT and monitoring of treatment. In  
5 KwaZulu-Natal, Eastern Cape and Gauteng DR-TB patients were initiated at decentralised DR-TB units but  
6 then referred to PHC facilities for daily injections, DOT and monitoring of sputum. On a monthly or bi-  
7 monthly basis, patients returned to the decentralised unit for review of their treatment based on the  
8 results of the monthly sputum monitoring at the PHC facility. The Northern Cape was providing DR-TB  
9 services mainly through an outreach model while preparing PHC facilities to start initiating patients.  
10  
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12

### 13 **Recruitment and sampling**

14  
15 We conducted a cross-sectional exploratory qualitative study in the Eastern Cape, KwaZulu-Natal,  
16 Northern Cape and Gauteng. The provinces as well as facilities in each province were purposively selected  
17 with the national DR-TB director and provincial TB coordinators as they represented the variety of  
18 different models of care being implemented across the country. Each province adapted implementation  
19 according to their own needs, capacities and resources, resulting in different models and varying levels of  
20 progress with implementation. Ten decentralised units, one central specialized unit and 12 primary  
21 healthcare facilities were selected for data collection in these four provinces. The provincial or district TB  
22 coordinator introduced the researchers to the facility manager for the first interview, after which  
23 purposive sampling was used to recruit healthcare workers, based on their designation (doctors and  
24 nurses) and placement (TB focal point). The final selection of healthcare workers was made on the day by  
25 the researchers LV and VM in discussion with the facility manager or head nurse and depending on  
26 availability of healthcare. We recognize that this process may have influenced the results. Interviews were  
27 conducted until data saturation was reached with a total of 43 healthcare workers, 9 operational  
28 managers, 6 provincial and district coordinators, 5 administrative staff and 2 social workers.  
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### 34 **Data collection**

35  
36 Qualitative data were collected from November 2015 until April 2017 using semi-structured interview  
37 guides that were developed for each type of staff category (nurse, doctor, operational manager,  
38 provincial/district coordinator) with questions relating to their knowledge and training, tasks, challenges,  
39 support and resources. Questions were open-ended and the interviewer led the interview as little as  
40 possible to make participants feel more comfortable in sharing their personal perceptions and  
41 experiences.  
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44

45 All interviews took place in the participant's place of work during work hours. The rooms where interviews  
46 took place were all private and sound proofed, and respondents seemed free to express themselves.  
47 Dates and times were arranged prior to the interview to accommodate the participants' work schedule  
48 and cause as little disturbance to the patient flow and facility staff as possible. Most interviews were  
49 recorded and transcribed. Some participants however did not feel comfortable being recorded. During  
50 these interviews, notes were taken. Data were constantly reviewed by LV, VM, and ML and emerging  
51 themes related to the original research question as well as new areas were taken into consideration for  
52 further interviews. Transcripts and notes were deidentified and stored on SAMRC's secured servers.  
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3 Validation of data was ensured by triangulation by means of a 'thick' description of the context, focused  
4 observation of daily practice and attendance of patient review meetings as well as staff meetings.  
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6

### 7 **Researcher characteristics and reflexivity**

8  
9 Interviews were conducted by 2 researchers, LV and VM, with a Master qualification in the field of social  
10 or health sciences and training in qualitative research in public health. Both researchers had no prior  
11 relationship with the selected facilities or their staff. As both researchers were introduced to the facilities  
12 by a provincial or district coordinator, they were aware of the possibility that they might be perceived as  
13 "sent by head office to check on facilities". In addition, LV was aware that being white and foreign, despite  
14 long residence in SA, might be received with feelings of suspicion or resentment linked to South Africa's  
15 history of apartheid and colonialization. Both researchers ensured that enough time was spent explaining  
16 the study as well as answering any questions regarding the study or the researchers' background to create  
17 transparency and reduce anxiety. While all but one participant were either Black African or Coloured<sup>1</sup>, no  
18 major differences were perceived in the type of responses in interviews conducted by LV, a white foreign  
19 female English speaking researcher, or VM, a black female Xhosa speaking researcher. From the interviews  
20 it became clear that participants felt free to express also negative views of the process, and no power  
21 differentials were evident.  
22  
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### 27 **Data analysis**

28  
29 Transcripts and notes were coded manually and analysed using thematic content analysis by LV (17).  
30 Transcripts were read and re-read to allow for familiarisation and to start the process of open coding.  
31 Coding was performed inductively, without following predetermined codes. Codes were grouped into  
32 clusters around similar and interrelated ideas from which several themes emerged. Preliminary analysis  
33 was performed by LV and reviewed by ML, SA and WZ, following which the analysis was revised.  
34  
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36

### 37 **Patient and Public Involvement**

38  
39 The national DR-TB coordinator as well as provincial TB coordinators were involved in the selection of  
40 the DR-TB facilities for the study. Patients and the general public were however not involved in the  
41 design or planning of the study.  
42

### 43 **Ethical considerations**

44  
45 The study was approved by the Ethics Committee of the South African Medical Research Council (EC023-  
46 8-2015). All participants were given informed consent forms which were read together with the  
47 participant and explained in detail before being signed. Participants were informed about the purpose of  
48 the study, procedures involved, risks and benefits of the study, and their rights as participants. The right  
49 to decline participation was emphasised, as well as an assurance given that the decision not to participate  
50 would not affect their work or relationship with superiors, colleagues and patients. Participants were  
51 given an assurance of confidentiality and strict protection of collected data.  
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## 55 **RESULTS**



Between November 2015 and April 2017, 67 interviews were conducted with 43 healthcare workers (HCWs), five administrative staff, two social workers, nine operational managers and six provincial/district TB coordinators at ten decentralised units, one central specialized unit and 12 primary healthcare facilities in four provinces in South Africa: Eastern Cape, KwaZulu-Natal, Gauteng and Northern Cape. For the purpose of this article and its focus on experiences of HCWs and facility management of the introduction and implementation of DR-TB care in their facility, we excluded the interviews with administrative staff and social workers as these had a different focus. We included interviews with TB coordinators to allow for their response to the stated challenges. Two nurses were interviewed twice because of the depth and richness of their knowledge of the local context. We therefore had a total of 59 interviews in the analysis. (Table 1)

Several themes emerged from the interviews relating to operational challenges, introduction of DR-TB care, leadership, training, human resources, infection control and infrastructure, and finances and resources. For this manuscript, however, we focused on those related to the introduction of DR-TB care in the facility and support during the implementation, as these came up strongly in the data, and raised several implications for effective patient care.

Table 1: Details of interviews

	Nurse	Doctor	Facility Manager/ CEO	Provincial/District TB coordinator	Total participants	Total interviews
Eastern Cape	10	3	3	1	16	17
KwaZulu-Natal	2	2	2	1	7	7
Gauteng	13	0	3	3	19	20
Northern Cape	11	2	1	1	15	15
Total	36	7	9	6	57	59

Three main themes relating to the introduction and implementation of DR-TB care in the facility emerged from the analysis:

- 1) Introduction of DR-TB care in the facility: "They just dropped it on us".
- 2) Support from district and province: "We never hear from them".
- 3) Inadequate coordination and integration between the DR-TB programme and other healthcare services: "Once we refer them back, we lose control of them".

#### 1) Introduction of DR-TB care in the facility "They just dropped it on us"

Healthcare workers in all four study provinces remarked that the introduction of DR-TB care in their facility came with little warning or engagement from district or provincial levels. In most facilities, treatment and care for DR-TB patients was simply added to the workload of the TB (and/or HIV) room.



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2  
3 *They told us like a week or towards the end of September that we will be starting in October, it was hectic.*  
4 *They called our acting CEO, they called her over the phone to tell her that we need to (start initiating DR-*  
5 *TB patients). (Nurse, decentralised unit)*  
6  
7

8 Many healthcare workers felt that these decisions were taken over their heads, even though it affected  
9 their daily work and their own personal health, creating anxiety and tension among healthcare workers.  
10 Especially healthcare workers at PHC facilities were agitated about the manner in which decisions were  
11 made. While most HCWs at decentralized DR-TB units mentioned some previous experience with drug-  
12 resistant TB patients, the majority of HCWs at primary healthcare level did not have this experience and  
13 expressed concern with the sudden addition of DR-TB patients to their daily routine.  
14  
15

16  
17 As one healthcare worker remarked:

18  
19 *They just dropped it on us, without no explanation, the one moment I had nothing the next moment I have*  
20 *eight patients. (Nurse, PHC)*  
21

22  
23 TB coordinators explained that NIMDR (nurse initiation of DR-TB) training had been organised by the  
24 National Department of Health, as well as a readiness assessment of facilities earmarked for the initiation  
25 of DR-TB, albeit with the necessary complications:  
26

27  
28 *The readiness assessment was actual done after some of the decentralisation processes were started,*  
29 *which I think it should have been the first thing before any implementation was done. (TB coordinator)*  
30

31  
32 *The district was trained by National. The only problem is that when training is done only a certain number*  
33 *of staff can attend which is then limiting. Like maybe they will say 1 candidate per facility. They started by*  
34 *training the managers and HAST coordinators, then nurses and doctors. (TB coordinator)*  
35

## 36 **2) Support from district and province: “we never hear from them”**

37

38 At a district level, the implementation of decentralisation is the responsibility of the district TB  
39 coordinator. He/she is responsible for informing, training and supporting the decentralised DR-TB units  
40 and PHC facilities that are providing DR-TB care. Healthcare workers in the TB room particularly felt that  
41 they needed the support from the TB coordinator to guide them through the changes, to monitor that  
42 they are doing it right, and to assist them with logistical and patient-related challenges. Most healthcare  
43 workers and facility managers, however, mentioned a lack of support from the district.  
44  
45

46  
47 *It was forced upon us. We’re afraid of initiating DR (-TB treatment) because of the side-effects. How to*  
48 *manage all this? We had a quick training but nobody walks you through it on the job. Then something goes*  
49 *wrong and people litigate against the department and the nurse is held responsible. (Nurse, PHC)*  
50

51  
52 *The challenges that we have with the district coordinator... She does not come to visit us. She doesn’t come*  
53 *to support us. She doesn’t at all. So now we end up not knowing whether we are right or we are wrong.*  
54 *(Nurse, decentralised unit)*  
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3 While participants commended the provincial department of health for supporting the facilities with  
4 equipment such as the Kudu Wave (portable audiometer) and laptops, and providing training for DR-TB,  
5 continuous support and presence from the province also seemed to be lacking.  
6  
7

8 *Provincial people come down here with a book and write down challenges but we never hear from them*  
9 *again. (Nurse, decentralised unit)*  
10

11 The lack of district support, however, seemed to be related to issues of capacity and time. In one district  
12 the post for TB coordinator could not be filled due to a moratorium on appointments.  
13  
14

15 *I can't say there's any support from the district. There's no TB coordinator in the district. They had one but*  
16 *the post is open again. You can't expect the district manager to visit all the institutions. They were*  
17 *supposed to make sure that they fill the post for TB. (CEO, decentralised unit )*  
18  
19

20 In two other districts, coordinators confirmed that they struggle to support the DR-TB facilities because  
21 of their workload.  
22  
23

24 *It's not only TB that I am looking at, I'm also looking at HIV, and HIV there's a lot of changes and things*  
25 *that's going on in HIV, new research is coming in, new developments is coming in, these developments*  
26 *need to be implemented so I think these are taking more of the time from the TB. (TB coordinator)*  
27  
28

29 **3) Inadequate coordination and integration between the DR-TB programme and general**  
30 **healthcare services: "Once we refer them back, we lose control of them".**  
31

32 Following initiation at the decentralised unit, patients are referred to their nearest primary healthcare  
33 facility (PHC) for daily observed treatment (DOT) and monitoring of treatment monitored by taking  
34 monthly sputum samples from patients. Healthcare workers at most decentralised units experienced  
35 problems with down-referral to the surrounding PHC facilities, saying that monitoring of sputum seldom  
36 happens.  
37  
38

39 *Basic things need to be available. The absence of the monthly sputums is a huge challenge. ... So sometimes*  
40 *you sit in OPD having to review a patient with a gap of two three months of no sputum. ... At the end of it*  
41 *all you are not doing justice to the patient because you are making decisions without the correct*  
42 *information. (Doctor, decentralised unit)*  
43  
44

45 In addition, healthcare workers at decentralised units complained of the refusal of PHC facilities to  
46 stabilise DR-TB patients before transferring them to the decentralised DR-TB unit.  
47  
48

49 *Patients are being referred here that are critically ill and not stabilized before transferring at the referring*  
50 *clinic. (Nurse, decentralised unit)*  
51  
52

53 *They are rushing; won't see the renal problem, they won't see jaundice in that patient, they won't see*  
54 *hypertension and diabetes in that patient, they won't see cancer, they won't see anything – the lump that*  
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3 *needs to be scanned or whatever. They would send– quickly rush that patient to us, to get rid of it. (CEO,*  
4 *decentralised unit)*

5  
6  
7 Healthcare workers at PHC facilities and at decentralised DR-TB units, however, painted a picture of little  
8 support and too much work for nurses in PHC facilities.

9  
10 *There's too much for the clinic sisters to do. They are making it practical for themselves to make it work.*  
11 *The sister is doing TB, child immunization, PMTCT, ARV. There's way too much for those sisters to cope at*  
12 *the clinic. How can this be resolved? More personnel. (Doctor, decentralised unit)*

13  
14  
15 Difficulties with cooperation and coordination were not limited to PHC facilities. Healthcare workers at  
16 decentralised DR-TB units spoke of serious difficulties with hospitals and other healthcare services when  
17 requesting services that they could not provide themselves but were essential to the well-being of the  
18 patient such as radiology, audiology and transport.

19  
20  
21 *You can make appointments make appointments and make appointments, but transport won't pitch*  
22 *because ambulance people are refusing to transport DR patients. Even with their masks on... (Nurse, PHC)*

23  
24  
25 *We send people to Hospital X for X-rays because we don't have a radiographer. But the radiographers*  
26 *there don't want to touch the patient because they are afraid of DR-TB. (CEO, decentralised unit)*

27  
28  
29 Patients being injected with Kanamycin as part of their treatment regimen need to undergo a hearing test  
30 on a monthly basis to monitor any hearing loss due to the ototoxic effect of Kanamycin. Several HCWs at  
31 decentralised units, however, reported challenges accessing audiology services, resulting in patients  
32 suffering hearing loss.

33  
34  
35 *It's a problem because there is no baseline and patients tend to report at a much advanced state. .... By*  
36 *the time they come back for the review they are completely deaf or are at a stage where it's so advanced*  
37 *that it's irreversible. (Doctor, decentralised unit)*

38  
39  
40 In the experience of staff at the decentralized units, many of these difficulties arise from fear and stigma  
41 of DR-TB with service providers that haven't received training for TB.

42  
43 *These doctors are scared of TB patients and refer them quickly. It's a problem with staff on that side. It's*  
44 *stigma of DR and TB. They dump the patient here after hours when doctors and staff are off. (Nurse,*  
45 *decentralised unit )*

46  
47  
48 The call for more training and education is supported by several TB coordinators.

49  
50 *The attitude towards TB doesn't help. If a patient is admitted in casualty at the general hospital for a*  
51 *broken femur. But when he is a DR patient, they will leave everything and refer the patient immediately to*  
52 *the TB hospital. A lot of education needs to happen. (TB coordinator)*

53  
54  
55 *More training is needed for everyone e.g. clinics, allied worker, staff in the hospital. There's still a lot of*  
56 *stigma on TB among hospital staff which makes it difficult. (TB coordinator)*

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3 One district coordinator, however, attributed the lack of support from other parts of the healthcare  
4 system to a lack of integration between district health services (DHS) and disease specific programmes  
5 such as DR-TB.  
6

7  
8 *District managers are accountable to the office of district health services (DHS), not to the programmes.*  
9 *We need to force that relationship so that programmes come together with DHS. (TB coordinator)*  
10

## 11 **DISCUSSION**

12  
13  
14 We reported experiences from healthcare workers, facility management and provincial and district TB  
15 coordinators of the introduction and implementation of DR-TB care at decentralised facilities. We focused  
16 on experiences relating to introduction of DR-TB care in facilities, support, and coordination and  
17 integration, as these were the strongest themes in the data.  
18

19  
20 A fundamental but often overlooked difficulty in 'change management' is the 'human factor', managing  
21 the impact that change has on employees.(18) Implementation often fails because it is conceptualised as  
22 a simple set of operational steps that need to be taken and doesn't take into account the effect that  
23 change will have on employees or the way employees attempt to cope with these changes.(18) Fear of  
24 the unknown and uncertainty can become sources of resistance. People need predictability, which has to  
25 do with their basic need for security.(19) Many healthcare workers and facility managers in our study,  
26 however, felt that decisions were taken over their head even though it affected their daily work and their  
27 own personal health. Especially among HCWs in primary healthcare facilities that did not have previous  
28 experience or training in treatment of DR-TB, the introduction of DR-TB services at the facility created  
29 anxiety and tension, which can result in resistance against or adaptation of the new service, which in turn  
30 can lead to sub-standard quality of care. Several studies in South Africa have shown that when healthcare  
31 workers are not engaged with the development and implementation of a new policy, resistance can grow  
32 and affect the quality of the services they offer.(1, 20, 21) For example, the lack of consultation with nurses  
33 whose daily practices were to be affected significantly when free healthcare was introduced, resulted in  
34 nurses rationing services as a coping mechanism.(21)  
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40  
41 The need for intense and prolonged engagement with those that will be providing the new service is even  
42 more essential when the new policy concerns a value laden or stigmatised condition, as for example found  
43 with the implementation of a new policy to increase access to safe abortions where healthcare workers  
44 outright refused to offer the service.(1) Similarly, in our study, the introduction of care for DR-TB, an  
45 infectious and deadly disease that is difficult to treat, raised anxiety on both a personal level i.e. the fear  
46 of infection, and on a professional level i.e. the frustration of an increased workload. Frontline providers  
47 need to be a part of the process and they need to be heard, since people are more likely to accept the  
48 forthcoming change if they know what to expect.(22) More engagement and addressing the fear that is  
49 evoked not only by the disease but also by the sudden change in daily practice, is therefore critical to  
50 ensure successful implementation of the new policy and prevent unintended negative consequences that  
51 can hamper quality of care for patients.  
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3 In addition, healthcare workers in our study also experienced isolation and a lack of support from other  
4 healthcare providers. The decentralisation of DR-TB has established a vertical programme with targeted  
5 delivery, and its own coordination, financing, information mechanisms, and lines of accountability. This  
6 vertical programme however has to function in an already established general district health system (DHS)  
7 which is not accountable to the DR-TB programme. As a result, as shown in our study, healthcare workers  
8 in the DR-TB programme found themselves in a position where they depended on the other healthcare  
9 services to provide effective care to their patients but in many cases were at the mercy of these services  
10 and their willingness to assist. Several studies have reported on similar problems with referrals between  
11 different facilities during centralized DR-TB care, resulting in a lack of continuity of care, and negative  
12 consequences for patients.(23-25). While decentralisation inherently requires strong coordination and  
13 effective referral between facilities to ensure continuum of care, our study shows that many of these  
14 problems with referral continued and might have worsened post-decentralisation.  
15  
16  
17  
18

19  
20 While much has been said and done about the integration of the HIV programme with the TB  
21 programme,(26, 27) and within the DHS,(28, 29) far less attention has been given to the integration of the  
22 DR-TB programme within the DHS. Insufficient integration of DR-TB services into existing TB, PHC and  
23 other general healthcare services and the resulting experiences of isolation and a lack of support from  
24 these services has been previously shown to affect treatment outcomes.(30) More research is needed to  
25 assess coordination and integration of DR-TB care, its effect on patient care and mechanisms to improve  
26 it.  
27  
28

29  
30 Like all qualitative studies, these results cannot be generalised beyond the specific facilities that  
31 participated in the study though theoretical transferability to similar contexts and issues is possible. Our  
32 study mainly focused on decentralised DR-TB units and less on PHC and other general healthcare facilities.  
33 As a consequence, our results show the point of view of healthcare workers in decentralised units and  
34 have to a minimal degree incorporated experiences from other healthcare facilities. In no way, however,  
35 does this study intend to cast blame on PHC and general healthcare facilities but recommends more  
36 research to obtain a holistic picture of the effects of decentralising DR-TB. In addition, we recognize that  
37 the sampling process i.e. the selection of provinces and facilities in agreement with national and provincial  
38 TB coordinators, may have influenced the results.  
39  
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41

## 42 **CONCLUSION**

43  
44 Frontline healthcare workers are key in the implementation of a new policy such as the decentralisation  
45 and deinstitutionalisation of DR-TB in South Africa. While this new model of care affects their daily work  
46 and personal health, healthcare workers in our study reported a lack of engagement when DR-TB was  
47 introduced in the facility, and feelings of isolation and a lack of support from the district and provincial  
48 health system as well as general healthcare services on which they rely such as audiology, radiology and  
49 patient transport.  
50  
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52  
53 Improved engagement with and support for frontline providers, and addressing the fear that is evoked  
54 not only by the disease but also by the sudden change in daily practice, are critical to ensure successful  
55 implementation of the new model of care and prevent unintended negative consequences that can  
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3 hamper quality of care for patients. In addition, improved coordination and integration of the DR-TB  
4 programme into the district health system can increase the levels of support needed by healthcare  
5 workers in the care of DR-TB patients and thereby improve the quality of care in a decentralised model of  
6 care.  
7  
8

## 9 **ENDNOTES**

10  
11 The terms Coloured and Black African were apartheid classifications of people in South Africa and  
12 continue to be used in South Africa as official and acceptable terms as they frame the historical and lived  
13 experience of South Africans.  
14

## 15 **CONTRIBUTORSHIP**

16  
17 Dr Loveday conceptualised and was the Principal Investigator (PI) on the study “Monitoring the roll-out of  
18 new models of care for MDR-TB patients in South Africa” which provided the data for this manuscript.  
19

20  
21 Ms Lieve Vanleeuw conducted interviews and collected data for aforementioned study. Ms Vanleeuw  
22 analysed the data and drafted the manuscript.  
23

24  
25 Dr Zembe-Mkabile and Associate Professor Atkins, together with Dr Loveday, reviewed and edited the  
26 manuscript multiple times and provided guidance to Ms Vanleeuw.  
27

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29  
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31 interviews for the study.  
32  
33

## 34 **COMPETING INTERESTS**

35  
36 None declared.  
37

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39  
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42 Partnership. The funders had no role in study design, in the collection, analysis, and interpretation of data;  
43 in the writing of the report; or in the decision to submit the paper for publication. All researchers were  
44 independent of funders and sponsors.  
45  
46  
47

## 48 **DATA AVAILABILITY STATEMENT**

49  
50 No data are available  
51

## 52 **FIGURES AND TABLES**

53  
54  
55 Figure 1: Units for the decentralised management of DR-TB.(3)  
56  
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Table 1: Details of interviews

For peer review only



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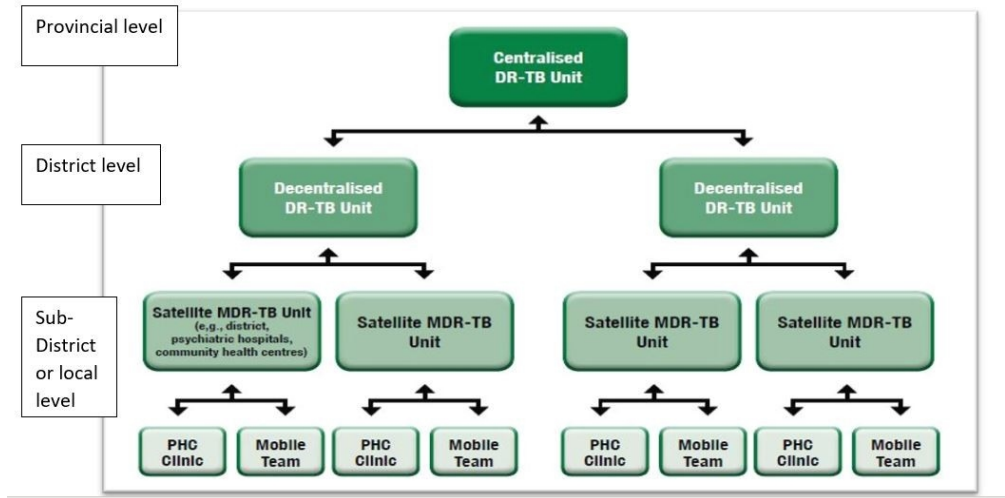


Figure 1: Units for the decentralised management of DR-TB.(3)

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## Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

### Title and abstract

<p><b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1, 4
<p><b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 2

### Introduction

<p><b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 4, 5
<p><b>Purpose or research question</b> - Purpose of the study and specific objectives or questions</p>	Page 4, 5

### Methods

<p><b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Page 6
<p><b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 7
<p><b>Context</b> - Setting/site and salient contextual factors; rationale**</p>	Page 6
<p><b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Page 6
<p><b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Page 8
<p><b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Page 7

1 2 3 4 5	<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 7
6 7 8	<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 6 - 8
9 10 11 12	<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 8
13 14 15 16	<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 8
17 18 19 20	<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 7

## Results/findings

23 24 25 26	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 8 - 12
27 28 29	<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 8 - 12

## Discussion

32 33 34 35 36 37	<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 12 - 14
38 39	<b>Limitations</b> - Trustworthiness and limitations of findings	Page 14

## Other

42 43 44	<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 14
45 46	<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 14

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

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