

RESEARCH ARTICLE

Long-term quality of life after obstetric intensive care unit admission: A cross-sectional cohort study

Karishma P. Ramlakhan^{1,2}  | Johanna A. van der Zande^{1,2} | Jolien W. Roos-Hesselink¹ | Arie Franx² | Jérôme Cornette²

¹Department of Cardiology, Erasmus MC, University Medical Centre Rotterdam, Rotterdam, The Netherlands

²Department of Obstetrics and Fetal Medicine, Erasmus MC – Sophia's Children's Hospital, University Medical Centre Rotterdam, Rotterdam, The Netherlands

Correspondence

Karishma P. Ramlakhan, Department of Cardiology, Erasmus University Medical Centre, Rg-419, P.O. Box 2040, 3000 CA Rotterdam, The Netherlands.

Email: k.ramlakhan@erasmusmc.nl

Abstract

Objective: To assess the long-term quality of life (QoL) after obstetric Intensive Care Unit (ICU) admission.

Design: Cross-sectional survey study.

Setting: Tertiary care centre.

Population: Women admitted to the level 3 ICU during pregnancy or ≤ 6 weeks postpartum, between 2000 and 2015.

Methods: Quality of life measures were compared with the population reference values. Associations with baseline ICU parameters were assessed with multivariable linear regression. Patient-reported outcome and experience measures (PROMs/PREMs) were described.

Main Outcome Measures: Quality of life according to the Linear Analogous Scale (LAS), the Satisfaction with Life Scale (SWLS) and the SF-36 questionnaire; PROMs/PREMs using the Pregnancy and Childbirth outcome set of the International Consortium for Health Outcomes Measurement.

Results: Of all 265 obstetric ICU admissions, 230 were eligible and 94 (41%) were included (median follow-up time 14 years). The LAS (75.7 versus 78.7, $p = 0.077$) and SWLS (25.2 versus 26, $p = 0.176$) sum scores were not different from the population reference values. The SF-36 subdomains bodily pain (55.3 versus 73.9), general health (58.2 versus 73.9) and vitality (56.9 versus 69.1) were lower than the reference values (all $p < 0.001$). PROMs/PREMs were low in 46.2% for pain, 15.1% for depression, 11.8% for satisfaction with care and 52.7% for healthcare responsiveness. An indirect obstetric ICU admission diagnosis was independently associated with a reduced physical health score ($B -1.7$, 95% confidence interval [CI] -3.4 to -0.1) and severe neonatal morbidity with a reduced mental health score ($B -6.6$, 95% CI -11.3 to -1.8).

Conclusion: Obstetric ICU admission is associated with reductions in long-term physical health QoL and in some patients with mental health QoL. We suggest multidisciplinary rehabilitation and long-term psychosocial support.

KEY WORDS

intensive care unit, pregnancy complications, quality of life

1 | INTRODUCTION

Intensive Care Unit (ICU) admission during pregnancy or postpartum is a deeply distressing event and is associated

with substantial maternal and perinatal mortality and morbidity.¹ The long-term impact of an obstetric ICU admission on a woman's physical and psychological quality of life (QoL) is not known. A few studies have addressed QoL after

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a maternal near-miss, which is defined as a life-threatening complication during pregnancy, labour or postpartum.² Although ICU admission is defined as a maternal near-miss,³ not all near-misses require ICU admission and therefore less severe obstetric complications are also included in these studies.⁴

There are two previous studies on QoL after obstetric ICU admission, which report data up to 5 years after delivery.^{5,6} This time frame may be too short to evaluate the long-term impact of the associated complications, such as the loss of a child, hysterectomies, colostomies, amputations or organ transplants.¹ Additionally, the previous studies used general and traditional QoL instruments such as the Short Form Health Survey (SF-36) but no pregnancy-specific instruments. Patient-reported outcome and experience measures (PROMs and PREMs) have not yet been reported, despite their growing importance in the evaluation of healthcare quality. Lastly, ICU admission has a physical and emotional impact on the patient's family members.⁷ The effect may be more pronounced in the context of a pregnancy because it involves both mother and (unborn) child, but there are no data on the QoL of the woman's partner.

The aim of this survey study is to examine the long-term QoL of women who survive an obstetric ICU admission and to assess which baseline and ICU factors are associated with reduced QoL. Additionally, we report PROMs and PREMs on pregnancy outcomes and assess the QoL of the partner.

2 | METHODS

2.1 | Study design and study sample

A cross-sectional survey study was performed in the Erasmus MC, a tertiary care centre in the Netherlands. The study was approved by the Institutional Review Board and informed consent was obtained. The study cohort has been described in detail in a previous publication¹ and included all women admitted to the level 3 ICU during pregnancy or ≤ 6 weeks postpartum, between 1 January 2000 and 31 December 2015. Women admitted to the level 2 obstetric high care ward were not included. Exclusion criteria for the survey invitation were death of the woman, the woman's previous objection to use her data for research purposes, a language barrier or the absence of contact information (email, phone number or home address). The woman's current partner was also asked for informed consent for an additional survey on his/her QoL.

2.2 | Data collection

Baseline characteristics and ICU parameters were collected from the patient record files.¹ The Dutch Personal Records Database (DPRD) was consulted on 7 July 2021 for survival status of the original study cohort. LimeSurvey was used to create and distribute the electronic survey. Because of the

long follow-up time, e-mail addresses or telephone numbers were often unavailable or out of date, so the survey was distributed through letters as well. Participants had 6 weeks to complete the survey after invitation and three reminders were sent.

2.3 | Study parameters

Baseline characteristics were collected for the entire original cohort of women and included age and parity at ICU admission, timing of ICU admission, mode of delivery and admission diagnosis, which was categorised as direct obstetric (e.g. postpartum haemorrhage), indirect obstetric (decompensation of underlying illness due to the pregnancy) or non-obstetric (e.g. trauma). ICU parameters included short-term (during or ≤ 1 year) mortality, hospital and ICU Length of Stay (LOS), APACHE II score, mechanical ventilation, haemodialysis, vasopressor or inotrope use, surgical and/or endovascular interventions, perinatal mortality, neonatal ICU (NICU) admission and neonatal severe morbidity. Long-term mortality was collected for the total cohort during the DPRD survival check, after which invitations for the survey were sent according to the exclusion criteria. Baseline characteristics for the partner were sex and age.

The study outcomes for the women were QoL measures and PROMs and PREMs for pregnancy outcomes. QoL of the participant was measured using the Linear Analogous Scale (LAS), the Satisfaction with Life Scale (SWLS) and the SF-36. PROMs and PREMs were measured with the International Consortium for Health Outcomes Measurement (ICHOM) standardised outcome measures for pregnancy and childbirth, using the T5 questionnaire set.⁸ Two additional open questions were created to evaluate what, in the respondent's view, had the largest negative impact on her QoL and how she could have been better supported. The study outcome for the partner was QoL measured with the SF-36 questionnaire.

2.4 | Survey details

Detailed information on the survey components and scoring systems can be found in Appendix S1.

2.5 | Statistical analysis

Baseline characteristics and ICU parameters were described and compared between participants and non-participants of the survey. QoL measures were compared based on the availability of stratified normative data, ideally with age bracket and sex-matched reference values (LAS).⁹ If these values were unavailable, sex-matched reference values and age bracket-matched reference values were used separately (SF-36 and SWLS sum score)^{10,11} or, if unavailable, the general Dutch population (SWLS subdomains).¹¹ For the comparisons with the age bracket reference values, weighted norm means were calculated

to match the age distribution in the study cohort. For PROMs and PREMs, the median scores and the proportions of low scores were described, as normative data do not yet exist.

Continuous data are presented as mean with standard deviation, or as median with IQR or range when skewed; we report the range for PROMs and PREMs because the extreme values are of interest in this context. Differences between the participants and non-participants were calculated using Student's *t*-tests or Mann-Whitney tests as appropriate. Differences between the participants and the reference values were calculated with the one-sample Student's *t*-test, comparing the means, as median reference values are unavailable. Categorical data are presented as percentages and compared using χ^2 tests. Two separate multivariable linear regression analyses were performed for the associations between baseline/ICU factors and the SF-36 summary scores (PCS and MCS), including variables that were $p < 0.1$ in the univariable analysis. The significance level was set at $p < 0.05$. Statistical analysis was carried out using IBM SPSS Statistics 25.0 (IBM Corp).

3 | RESULTS

Figure S1 shows the study sample selection, based on all obstetric ICU admissions between 2000 and 2015. The median follow-up time between the ICU admission and the survey was 14 (IQR 9–17, range 7–22) years. From the initial cohort of 265 women, 35 were excluded from the study: 13 (4.9%) early deaths and six (2.3%) late deaths, four patients with a language barrier and 12 patients without any contact information. The survey was sent to 230 women, and 94 women completed at least the SF-36 and the LAS (40.9% response rate).

Table S1 compares the baseline characteristics and ICU parameters of participants and non-participants (excluded patients and non-responders). The median age of the participants was 32 years (IQR 30–35) during the ICU admission and 46 years (IQR 41–50.3) at follow-up. Participants were most often admitted postpartum (84%) for direct obstetric complications (70.2%). The ICU LOS was 3 days (IQR 2–4); mechanical ventilation was required in 53.2% and surgical or endovascular interventions in 48.9%. Perinatal mortality (9.2% versus 22.3%, $p = 0.010$) and antepartum admissions (16% versus 30.4%, $p = 0.010$) were lower, and median age was higher (44 versus 46, $p = 0.024$) in the participants than in the non-participants, but otherwise the groups were similar. The higher incidence of perinatal mortality in the non-participating group was linked to maternal mortality in three of 35 cases; in the other 32 cases the mother was alive but did not respond to the survey invitation.

3.1 | Quantitative analysis

Figure 1 shows the QoL outcomes in the study participants (full results in Table S2). The median LAS was 80 (IQR 70–89) and not different from the sex- and age-matched reference value (75.7 versus 78.7, $p = 0.077$) (Figure 1A). The

SWLS sum score was 27 (IQR 22–30) and did not differ from either the age-matched or the sex-matched reference value. However, the items 'In most ways, my life is ideal' (4.7 versus 5.2, $p = 0.004$) and 'The conditions of my life are excellent' (5.1 versus 5.5, $p = 0.029$) were scored significantly lower than the reference value (Figure 1B). The SF-36 domains bodily pain, general health and vitality were scored lower than both the age-matched and the sex-matched reference values (all $p < 0.001$), but the other domains were not different (Figure 1C).

Figure 2A and Table S3 show the PROMs and PREMs for pregnancy outcomes and the proportion of low scores. Health-related QoL was considered low if the sum score was ≤ 19 and/or the pain score was ≥ 3 . We found low health-related QoL in 46.2%, which was wholly based on abnormal pain scores – the sum score was abnormal in only 3.2%. Complaints suggestive of a depressive disorder were found in 15.1%. Any urinary incontinence was reported in 28%, moderate or severe urinary incontinence in 18.3%, anal incontinence in 26.9% and pain during sexual intercourse in 30.1%. Low scores on PREMs included low maternal role confidence in 17.6%, low satisfaction with care in 11.8% and low healthcare responsiveness and shared decision making in 52.7% (subdomains are listed in Figure 2B). The most frequent low scores were given for the provision of information about different choices (40.2%) and shared decision making (40.2%).

Figure 3 shows the multivariable associations between baseline/ICU factors and the SF-36 summary scores (full results in Tables S4 and S5). An indirect obstetric ICU admission diagnosis was independently associated with reduced physical health (coefficient -1.7 , 95% confidence interval [CI] -3.4 to -0.1) and severe neonatal morbidity with reduced mental health (coefficient -6.6 , 95% CI -11.3 to -1.8).

In 47.9% ($n = 45$) of the participants, the partner completed the SF-36. Their median current age was 49.6 years (IQR 44.7–53.8) and they scored lower than the age-matched reference values on the domains of bodily pain and general health, but higher on physical functioning, social functioning, role limitations due to physical problems and role limitations due to emotional problems (Figure 1D and Table S6).

3.2 | Qualitative analysis

In all, 82 women (87.2%) answered the question on what the largest negative influence on their quality of life was. The four main themes were physical effects, psychological effects, healthcare factors and environmental factors, which could be further categorised in subthemes (Table 1A). Most participants described factors in at least two themes.

The most described physical effects were limitations due to underlying disease and fatigue, along with pain and memory problems. Psychological effects were mentioned most frequently, in particular the subtheme 'fear or anxiety'. Other subthemes were a lack of closure after the ICU admission and feelings of guilt or inadequacy. A few women used

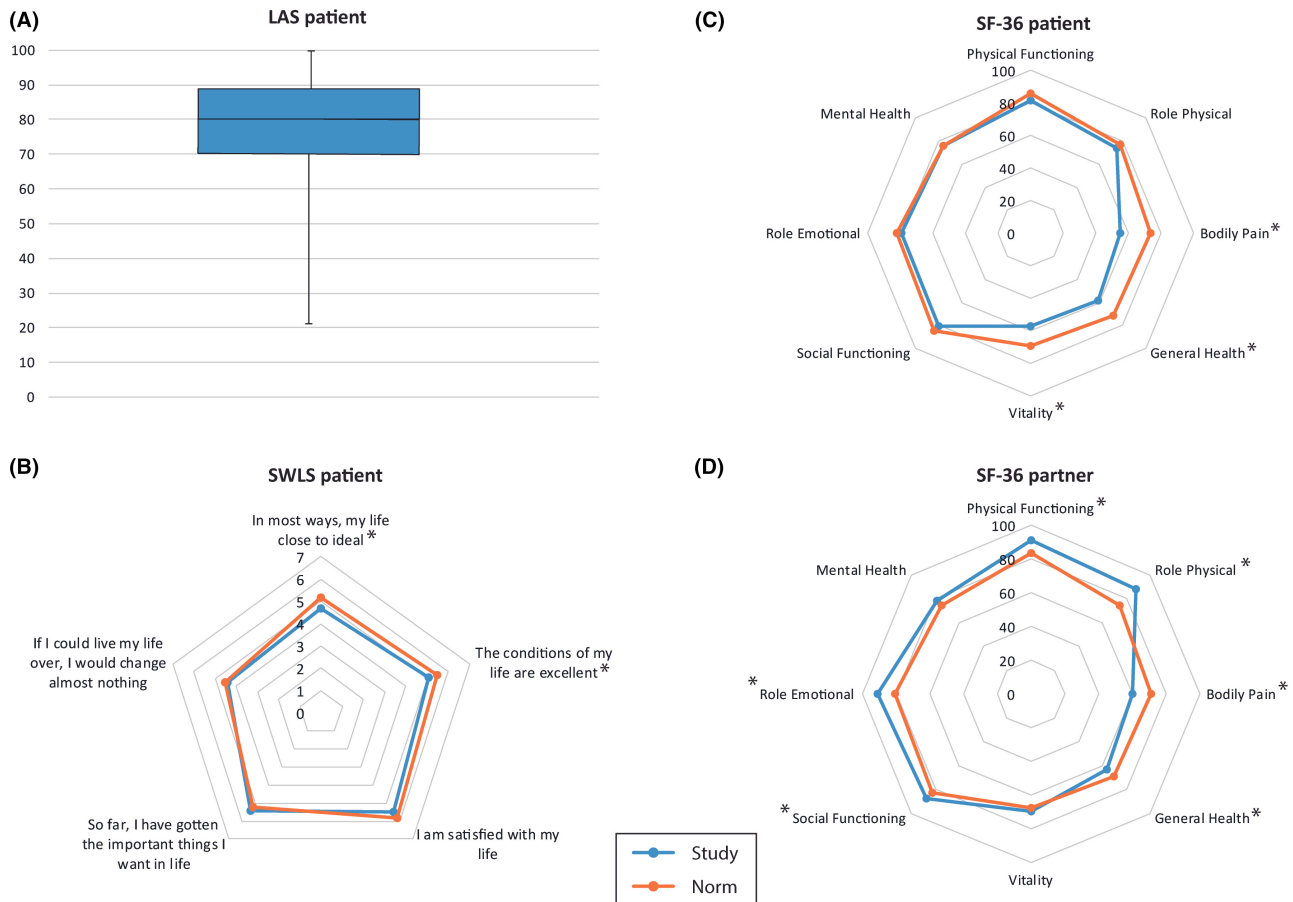


FIGURE 1 QoL after obstetric ICU admission compared with the Dutch population reference values. (A) Linear Analogous Scale (LAS) of the patients, 0–100, worst to best imaginable quality of life. (B) Satisfaction With Life Scale (SWLS) of the patients, 1–7, strongly disagree to strongly agree; compared with general population reference values. (C) SF-36 of the patients, 0–100, worst to best health-related quality of life; compared with age-matched reference values. (D) SF-36 of the partners, 0–100, worst to best health-related quality of life; compared with age-matched reference values.

the specific words ‘depression’, ‘post-traumatic stress disorder’ or ‘burnout’. The most frequently mentioned subtheme within the healthcare factors was the lack of physical or mental aftercare. A few women mentioned poor communication and a lack of shared decision making as reasons for not being able to process the ICU admission properly. Environmental factors were mentioned the least and included the loss of their child or worry about the child, relationship problems and a lack of environmental support.

In all, 76 women (80.9%) answered the question on how they could have been better supported. We identified three main themes: aftercare, healthcare support and practical support (Table 1B). The majority of women answered ‘I don’t know’ or had no suggestions.

Many women would have liked more aftercare, mentioning mental aftercare more than physical aftercare. Some wanted this to include their partner and family. Patient support groups and connecting with fellow patients were suggested specifically, along with the need for long-term follow-up. Healthcare support could be improved by more attention to communication and informing women better about the underlying disease and the expectations for

the future. Occasionally women mentioned the need for acknowledgement of (perceived) medical mistakes and follow-up visits with specifically involved healthcare workers. Practical support was not mentioned often and mainly concerned prolonged maternity care and employment support.

4 | DISCUSSION

4.1 | Main findings

This cross-sectional survey study performed 7–22 years after obstetric ICU admission shows that although overall long-term QoL is relatively good, several problem areas exist. Compared with the population reference values, women score suboptimal on several physical domains, such as pain, general health, vitality, incontinence and sexual function. A substantial proportion of women reported symptoms suggestive of a depressive disorder and decreased satisfaction with life. Women most often cited fear and anxiety as long-term physiological effects and expressed a need for long-term mental aftercare.

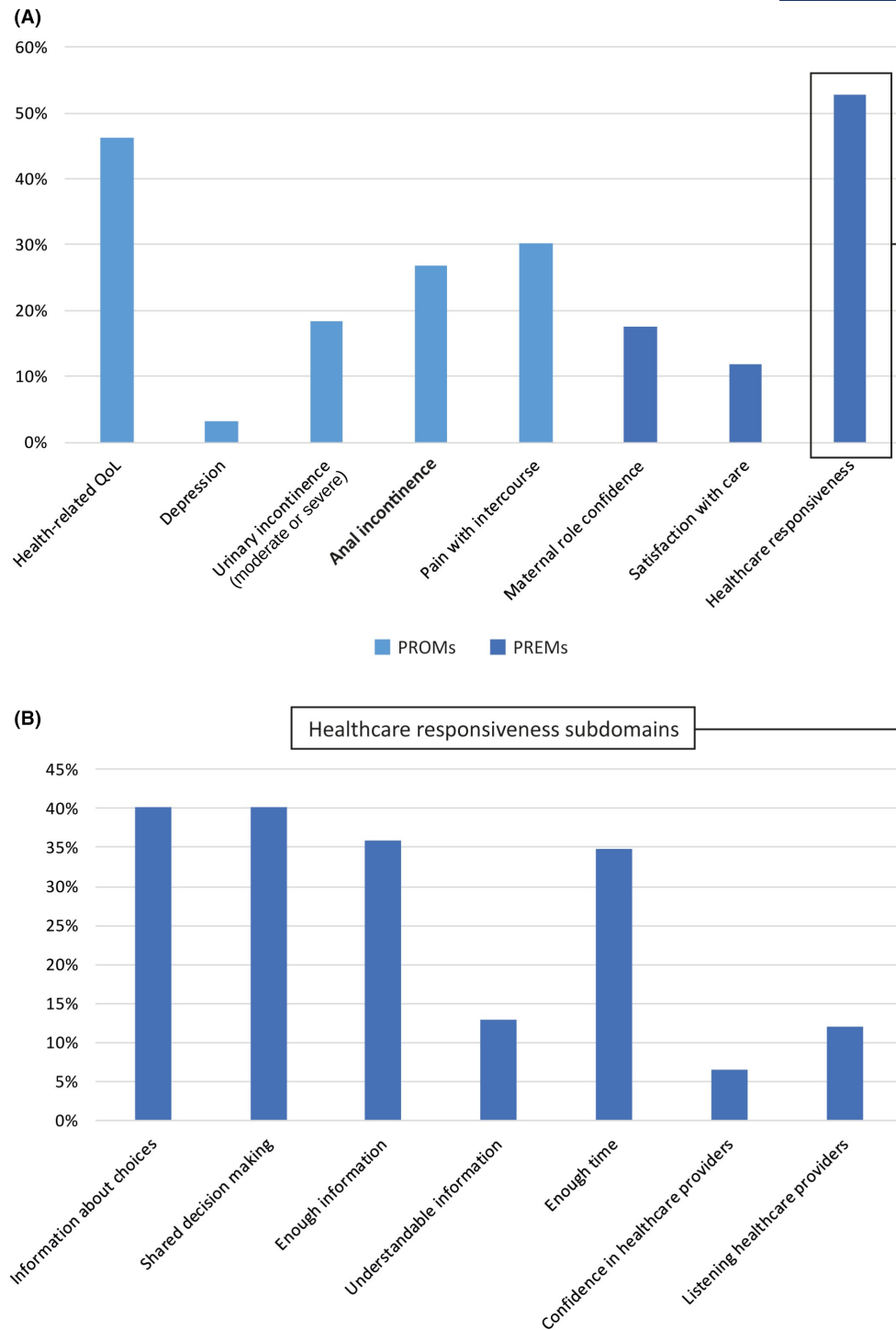


FIGURE 2 Low scores on patient-reported pregnancy outcome and experience measures. (A) PROMs and PREMs. (B) healthcare responsiveness subdomains, in order: 'Were you given information about your choices for maternity care?', 'Did you share in decision making about your care?', 'Were you given enough information to help you decide about your care?', 'Was the information understandable?', 'Did you get enough time to make your choices?', 'Did you have confidence and trust in the staff caring for you?', 'Did your healthcare providers listen to you?'.

4.2 | Interpretation

4.2.1 | Overall quality of life

A Finnish study shows no difference in health-related QoL 6 months after obstetric ICU admission in 81.6%, compared

with population reference values.⁶ The authors cited the low severity of illness in their cohort (ICU LOS 22 hours and APACHE III score 9) as a possible explanation,¹² but our results show that even in a more severely ill population, overall QoL remains good. This is different from the reduced overall QoL reported after maternal near-miss in studies from

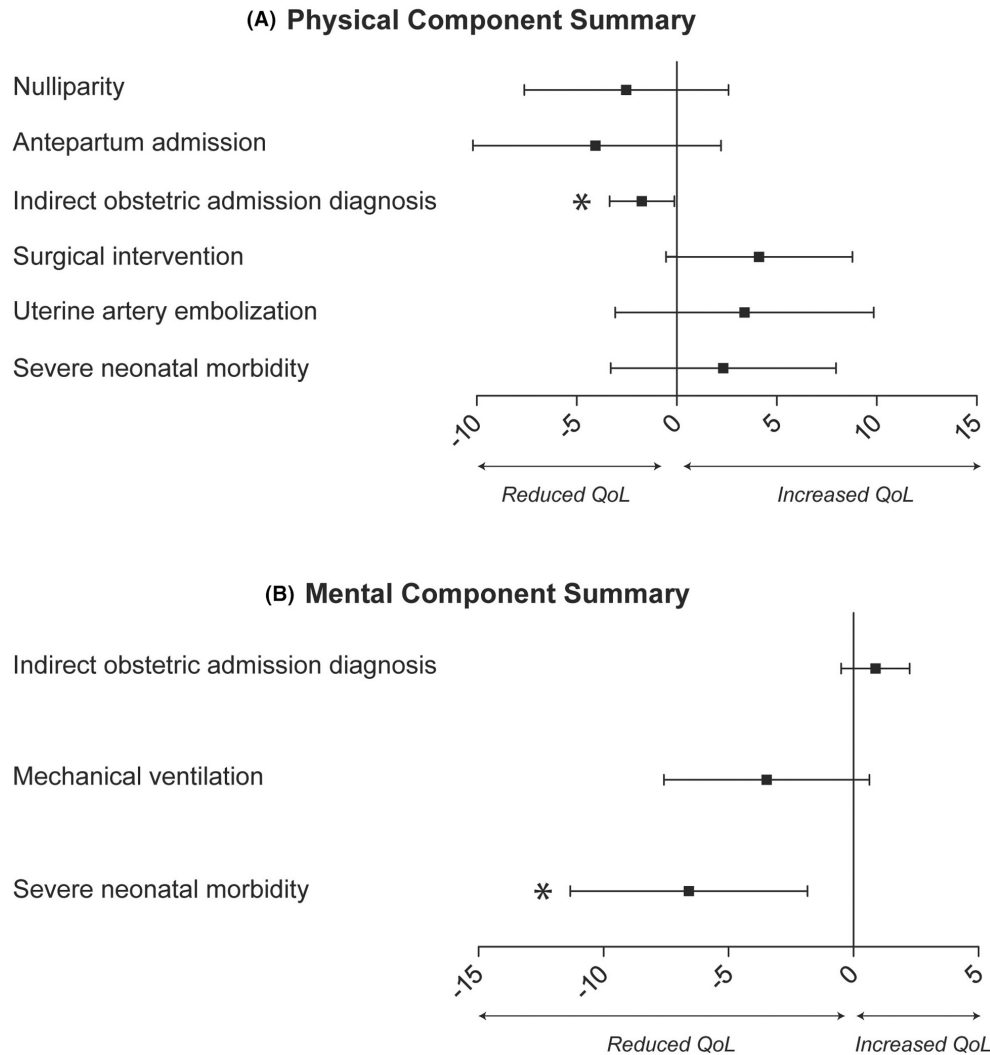


FIGURE 3 Multivariable linear regression analysis for associations with health-related quality of life as measured with the SF-36 summary scores. * $p < 0.05$. QoL, quality of life.

Burkina Faso¹³ 4–5 years after admission, and South Africa¹⁴ 1 year after admission. It seems plausible that there are more opportunities to recover from a maternal near-miss in high income countries; besides potential differences in (mental) healthcare availability and accessibility, studies from low/middle-income countries show far-reaching financial consequences after a near-miss that could have an additional detrimental effect.^{13,15}

We performed the first qualitative analysis on QoL in women after an obstetric ICU admission. The themes that could be identified from the women's answers correspond to Post-Intensive Care Syndrome (PICS), which is defined as 'new or worsening co-occurrence of physical dysfunctions, psychological disorders, cognitive impairments or failed social reconstruction with these impairments persisting beyond ICU and hospital discharge.'¹⁶ Timely recognition by healthcare professionals is important to reduce the impact of PICS.¹⁷

4.2.2 | Physical health

We showed that obstetric ICU admission is associated with a long-term detriment to several physical health domains, observed through multiple outcome measures. A Brazilian study comparing mothers after obstetric ICU admission with mothers after an uncomplicated birth (1–5 years after delivery) similarly found reduced scores for pain and general health, as well as physical functioning and role limitations due to physical problems.⁵ These factors were also commonly reported subthemes in our qualitative analysis. The Finnish study reported no difference on 'pain/discomfort' compared with the reference value, but this was scored with a single item on a 3-point scale only.⁶ We found an association with an indirect obstetric admission diagnosis, which involves women with comorbidities that were exacerbated by their pregnancy, leading to the ICU admission. These women should receive particular attention during follow-up,

TABLE 1 Qualitative analysis.

| Theme | Subthemes | Theme example quotes |
|--|---|--|
| A. Question 1 | | |
| <i>'What had the largest negative impact on your quality of life?'</i> | | |
| Physical effects | <ul style="list-style-type: none"> • Fatigue • Limitations due to underlying disease • Pain • Memory problems | <p>'After the admission on the ICU I developed memory problems that still persist today. They prevented me from going back to the job I had before the admission.'</p> <p>'I had hypoxia, one of the reasons why I was admitted to the ICU. There has been no further analysis for brain damage, despite my experiencing daily problems because of this. It feels like my brain is wired differently than before my illness.'</p> <p>'Because of my chronic disease I have very little energy and this is very bothersome for me, but especially for my family.'</p> <p>'The consequences of the stroke – no balance, loss of strength, coordination problems, jaw lock, etc.'</p> |
| Psychological effects | <ul style="list-style-type: none"> • Fear or anxiety • Depression • Feelings of guilt or inadequacy • Lack of closure • Major changes in way of life | <p>'The near death experience caused panic attacks even after 4 years, for which I still take medication.'</p> <p>'While recovering, we needed help taking care of my son. The relationship between me and my son is very good now, but I keep the feeling that I have not been able to give him enough love and security.'</p> <p>'I notice that the events still bother me and I've recently been referred to a psychologist because of burn-out symptoms. It had quite an impact on my family.'</p> <p>'I get sensory overload and fatigue from a nice visit with friends. My vocal chords are partially paralysed due to the mechanical ventilation. I used to sing in choirs and I cannot do that anymore, but my social life was largely based on that.'</p> <p>'I had difficulty accepting what happened to me. Your entire life changes. I was now dependent on my partner. You feel like you have fallen into a black hole. I felt like a burden to the world.'</p> |
| Healthcare | <ul style="list-style-type: none"> • Lack of physical or mental aftercare • Poor communication • Perceived medical mistakes • Lack of shared decision making • Loss of confidence in healthcare • Being seen as a 'study object' • Negative experience with a specific healthcare worker/centre • No (prolonged) maternity care at home | <p>'I was not seen as a person, but as a disease by many of the doctors.'</p> <p>'I did not know exactly what happened to me. I would have liked to have this on paper and discussed it a follow-up visit after discharge.'</p> <p>'It was not clear what was wrong with me and the doctors were not in agreement. There was no home care and no aftercare, no guidance and no anticipation [on the long-term consequences]. I had to figure everything out by myself and I've struggled for years.'</p> <p>'I do not have a lot of confidence in my body and in doctors anymore.'</p> |
| Environment | <ul style="list-style-type: none"> • Loss of the child • Worry about the child • Relationship problems • Lack of support from the environment • Loss of employment or social activities | <p>'The loss of a child...'</p> <p>'The death of my daughter, a brain tumour 2 years later, a divorce and all the misery surrounding it.'</p> <p>'[I had] a sick child in the NICU, while I was still recovering. I lived from blood transfusion to transfusion, was extremely tired but went to my child every day anyway. If I could not come one afternoon or evening, I was made to feel guilty for this.'</p> <p>'I felt abandoned after my delivery. In my environment there was absolutely no cooperation and understanding for what I had experienced and felt. I had to do everything myself after the hospital admission because I was not eligible for assistance at home anymore. I was not taken seriously by my employer and the company doctor and I quit my job.'</p> <p>'All activities (social and sports) and my job that I had to stop because of the problems with my cardiopulmonary function.'</p> |
| B. Question 2 | | |
| <i>'How could you have been supported in this matter?'</i> | | |
| Aftercare | <ul style="list-style-type: none"> • Mental aftercare • Physical aftercare • Specific examples: peer support groups, family therapy | <p>'I would have liked better and more personal aftercare. There should be more attention to what was a traumatic experience for me, seeing my daughter fight in the NICU and being admitted to the ICU myself as well. [I would have liked] conversations with experienced healthcare workers who know how intense an ICU admission can be, in particular after birth.'</p> <p>'If a psychologist had been sent to me a week after discharge, the past 16 years might have been a lot better for me and my family. Family coaching would have been relevant as well, my relationship failed after all this. With more guidance things might have been different.'</p> <p>'Psychological support! Due to the traumatic event I developed post-traumatic stress disorder and eventually followed therapy years after delivery. I kept having nightmares. Good help and aftercare from the beginning might have prevented it.'</p> |

(Continues)

TABLE 1 (Continued)

| Theme | Subthemes | Theme example quotes |
|--------------------|--|--|
| Healthcare support | <ul style="list-style-type: none"> Better communication and information Shared decision making More mother–child bonding opportunities Acknowledgement of mistakes or complications (Long-term) follow-up visits with the involved healthcare worker (e.g. to fill the memory gaps) | <p>‘Better guidance and understanding for my feelings and the acknowledgement of mistakes in judgement.’</p> <p>‘The documentation of my time in the ICU, to help me process this.’</p> <p>‘I would have liked to receive more information about how I should see myself after an ICU admission. Which lifestyle matters are important? Who is following up my health?’</p> <p>‘I feel like I was supported well.’</p> |
| Practical support | <ul style="list-style-type: none"> (Prolonged) maternity care Employment support | ‘Maternity care after discharge would have been nice.’ |

Abbreviation: (N)ICU, (neonatal) intensive care unit.

rehabilitation and physical therapy. In general, there should be more attention paid to the treatment and (secondary) prevention of incontinence, as high rates of both urinary incontinence (any in 28%, moderate or severe in 18.3%) and anal incontinence (29%) were reported. In comparison, the long-term incontinence rates after birth in the general population are 15.9%–21% for any urinary incontinence,¹⁸ 6.2%–8.7% for moderate or severe urinary incontinence¹⁸ and 15.8%–17.8% for anal incontinence,¹⁹ depending on the mode of delivery. A substantial number of women (30.1%) had complaints of dyspareunia, more than expected from the background rate of 21%.²⁰ Although illness can have a large impact on sexuality, the topic is often overlooked by healthcare professionals – initiating discussion of the subject could help to normalise the subject and to provide patient education and treatment options.²¹ The most frequently mentioned physical complaint in the qualitative analysis is long-term fatigue. Unfortunately, there are no studies that have investigated how to prevent this common PICS symptom, but education, acknowledgement and support can help to improve coping and manage expectations.

4.2.3 | Mental health

In our study no association was found with reduced overall mental health QoL, which is in line with the Finnish and the Brazilian cohorts^{5,6} but not with several studies on maternal near-miss in LMIC.^{14,15,22,23} However, we found a decreased satisfaction with life on certain aspects and complaints suggestive of depressive disorders in 15.1%, which is alarming. For some women, the ICU admission had a severe impact and we need to support these women better. Severe neonatal morbidity, such as extreme prematurity, has previously been shown to be associated with maternal depression and mental health complaints in the postpartum period.²⁴ We show that an association with adverse outcomes remains even years afterwards, as severe neonatal morbidity was independently associated with a reduced mental health score. It is notable that perinatal death was not found to be associated with reduced mental health, but there were significantly

fewer women with perinatal deaths among the participants. This was not due to concomitant maternal deaths (which were, by definition, in the non-participating group), as the majority of women with perinatal deaths were alive but declined to participate. This might have led to selection bias and exclusion of some heavily burdened women. Possibly, being reminded about the ICU admission was painful or too big a burden for these women. As proposed by the women themselves in our qualitative analysis, long-term psychosocial support should be offered after any obstetric ICU admission, in particular for women with perinatal deaths or severe neonatal morbidity.

4.2.4 | PROMs/PREMs

We are the first study to report PROMs and PREMs after obstetric ICU admission, with a substantial proportion of women reporting low scores. Role confidence may be low because the mother may have missed the first period of her child's life while she was in the ICU.²⁴ There is room for improvement in the satisfaction with care and shared decision making may be a place to start: 52% scored at least one ‘no’ on the healthcare responsiveness items. This was further confirmed by the qualitative analysis. Attentive communication with the patient is crucial in this period characterised by lack of control and autonomy. However, there are inherent complicating factors in the ICU setting, such as periods of sedation, emergency situations and the ICU-associated memory problems.²⁵ Healthcare responsiveness may nevertheless be improved by using an integrated approach including the patient's values and needs, educating ICU staff on effective communication, using alternative communication methods for ICU patients that are temporarily voiceless due to medical intervention²⁶ or using specialised staff.²⁷

4.2.5 | The partner

Interestingly, we found that, similar to the women, the partners also reported decreased QoL on the domains bodily

pain and general health. However, they were more positive about their physical and social function and reported fewer limitations due to physical or emotional problems. Previous studies on psychosocial outcomes in caregivers of ICU survivors note increased depressive symptoms, activity restriction and decreased health-related QoL shortly after ICU admission that improve in time at medium-length (1 or 2 years) follow-up.⁷ Our findings show that at long-term follow-up, QoL of the partner has improved and is now relatively good.

4.2.6 | Clinical implications

We found long-term adverse QoL outcomes after obstetric ICU admission that fit PICS, but also include complaints that are pregnancy-related, such as urinary and anal incontinence and decreased sexual function. We propose standardised follow-up in a multidisciplinary setting, using the complementary strengths of obstetric, ICU, psychosocial and rehabilitation caregivers. In the short term, this should ideally include the caregivers who were personally involved. In the long term, a dedicated team with specialised knowledge on all involved domains (which may become less or more relevant with time) may be best suited to support the woman and her family. Adequate treatment of any underlying disease is also important, as shown by the association between an indirect admission diagnosis and reduced physical QoL.

4.3 | Strengths and limitations

The study is limited by its single-centre design and its tertiary setting, which limits generalisability. The collection of baseline/ICU data was performed retrospectively, which is susceptible to bias. Surveys are inherently susceptible to bias as to who chooses to participate; however, differences at baseline were very limited. The response rate was limited by the long follow-up time, as contact information was not always up-to-date. Considering that severe neonatal morbidity was associated with reduced mental health, the reported mental health complaints may be underestimated, as women with perinatal deaths completed the survey less often. Not all surveys were validated in the obstetric population specifically. However, the general QoL measurement tools have already been broadly used and validated in a multitude of populations, from national background populations to ICU patients.^{11,28} The ICHOM T5 set was specifically developed for the obstetric population and uses validated PROMs, whereas the PREMs have yet to be validated. The PROMs and PREMs do not always have reference values as yet, so it is unclear to what extent low scores are attributable to the ICU admission. Because of the long follow-up time, the results may not reflect current practice, but this is intrinsic to performing a study on long-term effects. This study cannot distinguish between the effect of the condition requiring ICU admission and the effect of the ICU environment and is therefore unable to draw a causative link between the ICU admission and reduced QoL.

In conclusions, specific QoL domains are suboptimal in the long-term after obstetric ICU admission and we propose aftercare by a multidisciplinary team, including obstetric, ICU and psychosocial caregivers. Physical complaints include domains such as pain, general health, vitality, incontinence and pain with intercourse. Overall mental health scores were not diminished, but a substantial proportion of women had complaints of depression, fear and anxiety. Counselling, physical and psychosocial therapy could be helpful. Special attention should be given to women with an indirect obstetric admission diagnosis or with adverse neonatal outcomes, as these were independently associated with reduced physical health and mental health, respectively. The reported low scores on satisfaction with care and shared decision making, combined with the healthcare factors that women note as points for improvement, should prompt an evaluation of current communication practices and a future focus on integrated and patient-centred care.

AUTHOR CONTRIBUTIONS

Study design: KPR, JC, AF. Data collection and analysis: KPR. Data interpretation: all authors. Draft of article: KPR, JAZ. Critical revision, editing and approval of the final article: all authors.

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None.

FUNDING INFORMATION

There are no funding sources to declare.

CONFLICT OF INTEREST STATEMENT

None declared. Completed disclosure of interest forms are available to view online as supporting information.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS APPROVAL

This study complies with the Declaration of Helsinki. The study was approved by the Erasmus MC ethics committee under reference number (MEC-2021-0367) on 11 June 2022 and informed consent was obtained from the study participants.

ORCID

Karishma P. Ramlakhan  <https://orcid.org/0000-0002-6741-2603>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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