PB-PG-0408-14245 – NIHR Research for Patient Benefit Programme – Final report

Project title: How can we improve mental health care of mentally ill mothers in prison and the outcomes for them and their children?

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Plain English summary

Our research team previously carried out two studies (2003 and 2007) of the mental health of mothers in prison, the first study women in prison mother and baby units (MBUs), and the second sampled women who were separated from their children aged under 18 months. The current study was a follow up of these two groups of women. 130 of 167 women agreed to be contacted for follow up at the time of the original studies. 87 were located and 60 completed an interview which included. When first interviewed, most of these women were suffering from some form of mental illness that had not been identified or treated by the prison NHS services. Those who were separated from their children had higher levels of mental disorders and more complex problems. Mental health problems in mothers with young children are known to have serious long term effects on the mother's health and on the child's development. Previous findings were supported by the current findings of undiagnosed and untreated mental disorders. Prison MBUs are supportive environments and may contribute to reducing re-offending. Women who had spent time in prison MBUs were far more likely to be living in their own home, and have care of their children. Women's experiences of mental health care in prison were felt to be inferior to care outside. One of the greatest barriers to care was lack of continuity between prison and community services, and this was further exacerbated by homelessness, which was experienced by large numbers of women and children on release from prison.

Keywords

Mothers, Prison, Mental health, Follow up, Offenders

Summary of research findings

Our previous studies identified high levels of unrecognised and untreated mental illness (60%) amongst women in prison mother and baby units (MBUs; Birmingham et al, 2004), and amongst women prisoners separated from their infants (90%) (Gregoire et al., 2010). Mental disorders cause suffering, lead to higher rates of offending, social disadvantage and exclusion. Parental mental illness impacts on child development particularly if unrecognised and untreated, or accompanied by substance abuse or personality disorder (Goodman & Gotlib, 2002; Rutter & Quinton 1984).

The current follow up study examined maternal and child outcomes in women and children from these previous an average of 5.71 years after the original study.

Design

130 participants from 2 previous studies: women in prison MBUs ('MBU') and women separated from infants in prison ('separated') who consented to follow up

Tracing through multiple sweeps of:
Information provided by participants
Prison Service
GP/NHS records
Telephone directories
Electoral records
Facebook

Measures
Semi-structured interview including; demographic details, offending history, mental health needs, child care arrangements
Clinical Interview Schedule
Alcohol Use Identification Test
Severity of Dependence Questionnaire
Strengths and Difficulties Questionnaire
In-depth qualitative interview approximately 20 minutes
Information from GP record/inmate medical record
Information from child's GP record

Analysis

Quantitative data and analysis were managed using SPSS for Windows.
Qualitative data were managed using NVivo. Thematic framework was utilised.

RESULTS

Recruitment

First study: 55 (MBU); 112 (Separated)
Consent to contact: 38 (MBU); 92 (Separated)
Contact made: 29 (MBU); 58 (Separated)
Interviewed: 22 (MBU); 38 (Separated)
Deceased: 1(MBU); 2 (Separated)

Aim 1. Mental health and social outcomes of imprisoned mothers, and the health, social and developmental outcomes of their infants

Table 1 Social & demographic details

Mean age at interview: 31.13 years (SD 6.31), Median age 30 years (Range 21, 45)

Place of birth
England/Wales: Total = 53 (88%); MBU = 21 (95%); Separated = 32 (84%)
Irish Republic: NA

Ethnic origin
White:Total = 38 (63%); MBU = 12 (55%); Separated = 26 (68%)
Black: Total = 13 (22%); MBU = 4 (18%); Separated = 9 (24%)
Indian: Total = 1 (1%); MBU = 0; Separated = 1 (2%)
Mixed race: Total = 8 (13%); MBU = 6 (27%); Separated = 2 (5%)

Marital status
Single/separated: Total = 42 (71%); MBU = 15 (69%); Separated = 27 (71%)
divorced
Married/cohabiting: Total = 17 (29%); MBU = 6 (27%); Separated = 11 (29%); 1 Missing

Employment
Employed: Total = 4 (6%); MBU = 4 (18%)
Unemployed: Total = 53 (90%); MBU = 17 (78%); Separated = 36 (94%)
University: Total = 3 (4%); MBU = 1 (5%); Separated = 2 (5%)

Accommodation
Own home: Total = 43 (72%); MBU = 20 (91%); Separated = 23 (61%)
Unsettled (e.g. B&B): Total =10 (17%); MBU = 1 (4.5%); Separated = 9 (24%)
Homeless: Total = 5 (8%); Separated = 5 (13%)
Residential rehab: Total = 2 (3%); MBU = 1 (4.5%); Separated = 1 (3%)

*70% of participants reported being homeless at some point (55% MBU 74% separated)
*10 in prison at interview (1 MBU 9 separated)

Table 2 Current status of index child

Living: Total (n=61); MBU (n=22); Separated (n=39)
Mother: Total = 24 (40%); MBU = 17 (77%); Separated = 7 (18%)
Father : Total = 3 (5%); MBU = 2 (9%); Separated = 1 (3%)
Other family: Total = 11 (18%); MBU = 1 (4%); Separated = 10 (26%)
Foster care: Total = 6 (10%); MBU = 1 (4%); Separated = 5 (13%)
Adopted: Total = 15 (25%); MBU = 1 (4%); Separated = 14 (36%)
Unknown: Total = 2 (3%); Separated = 2 (5%)

Table 3 Strengths & Difficulties Questionnaire (SDQ)

35 (21 MBU 14 Separated) had care of/regular contact with the index child and completed the SDQ

Emotional
Borderline: Total = 1 (3%); Separated = 1 (7%)
Abnormal: Total = 2 (6%); MBU = 2 (10%)

Hyperactivity
Borderline: Total = 3 (9%); MBU = 3 (14%)
Abnormal: Total = 9 (26%); MBU = 6 (29%); Separated = 3 (21%)

Peer problems
Borderline: Total = 1 (3%); Separated = 1 (7%)
Abnormal: Total = 4 (11%); ; MBU = 4 (52%)

Conduct
Borderline: Total = 2 (6%); MBU = 1 (5%); Separated = 1 (7%)
Abnormal: Total = 9 (26%); MBU = 7 (34%); Separated = 2 (14%)

Total score
Borderline: Total = 4 (11%); MBU = 2 (10%); Separated = 2 (14%)
Abnormal: Total = 4 (11%); MBU = 3 (14%); Separated = 1 (7%)

30 gave permission for the child's GP to be contacted, 22 responded

Table 4 GP information on children

Total = 22; MBU = 16; Separated = 6
Health problems: Total = 9 (43%); MBU = 8 (53%); Separated = 1 (17%)
Delayed speech: Total = 3 (14%); MBU = 2 (13%); Separated = 1 (17%)
ADHD/concentration: Total = 3 (14%); MBU = 3 (20%)
Learning difficulties: Total = 1 (5%); MBU = 1 (7%)
Bedwetting: Total = 2 (10%); MBU = 2 (13%)

*All up to date with vaccinations except 1 from MBU study

Aim 2. The mental health and social needs of women during and after imprisonment

At the previous interview 52 (87%, MBU 20, 91%, Separated 32, 84%) of the participants had some form of mental disorder (neurotic, psychotic, personality, drug, alcohol). In the current study 13 (22%) had a score of 8+ on the AUDIT, suggesting drinking at hazardous levels (4, 18% MBU; 9, 24% separated). Separated participants had higher mean scores (M= 4.87, SD 10.25) than MBU participants (M=3.41, SD 6.04) but were not significant t(58) = -6.08, p> .05.

Table 5 Current Illegal drug use

Abusive/ dependent use
Benzodiazepines: Total = 4 (6%); Separated = 4 (11%)
Opiates: Total = 8 (13%); Separated = 8 (21%)
Cocaine: Total = 6 (10%); Separated = 6 (16%)
Cannabis: Total = 2 (3%); MBU = 2 (9%)

Table 6 CIS-R scores

Distribution of CIS-R scores
Mean (SD): 12.93 (10.70)
Median (range): 10.00 (0, 42)

Prevalence of neurotic disorders
Total depression: Total = 28 (47%); MBU = 5 (22%); Separated = 23 (61%)
1+ neurotic disorders: Total = 30 (50%); MBU = 7 (50%); Separated = 40 (67%)

58 participants gave consent to contact their GP, 49 responded. 31 (54%) reported a current or previous mental disorder (11, 50% MBU and 20, 53% separated). There was poor agreement between research diagnosis of mental disorders and GP diagnosis according to the kappa statistic = 0.19 (95% CI -0.05, 0.43).

Aim 3. Extent to which treatment needs were identified by NHS prison health services or local NHS health services

Table 7 Previous mental health treatment

Ever seen a psychiatrist: Total = 31 (52%); MBU = 7 (32%); Separated = 24 (63%)
Diagnosis: Total = 20 (33%); MBU = 4 (18%); Separated =16 (42%)

Currently taking prescription drugs for MH disorder
Total = 31 (52%)

There was poor agreement between research diagnosis of mental disorders and treatment received according to the kappa statistic = 0.11 (95% CI -0.08, 0.30).

Aim 4. Women's experiences and perceptions of health and social care provision for them and their children in prison and following release

Many who were pregnant and/or had children in prison described being treated differently by NHS staff, and a poorer level of care. Antenatal care and health care received by children in prison was reported to be as good as, or better than in the community.Many felt prison mental health care was inferior to that available outside. Some felt they had benefited from treatment and some not.

Prison MBUs and staff were seen as supportive. Being with their child made prison bearable and prevented a return to drugs/crime on release. Women separated from children in prison reported imprisonment often led to permanent loss of custody of children.Those who had had children removed often cited this as a reason for continuing addiction/offending.

Social support on release was non-existent. Lack of accommodation/homelessness was the problem most commonly reported.Councils and social services were unhelpful. Stable accommodation on release was needed and community MBUs for those with children.

A5. Perceptions of barriers to care and how these might have been overcome by NHS services

Lack of continuity of care was a major barrier for managing chronic mental health and/or addiction problems. Treatment for mental disorders in prison ended on release, with long waits for assessment in the community. Treatment for mental disorders in the community ended at imprisonment, with long waits for assessment in prison.

Those seen by different practitioners each time, said they did not want to repeatedly explain the often harrowing details of their experiences, so would cease to access services. Accessing care for themselves and their children was complicated through no address/long term homelessness.

Some refused mental health care, not wanting to disclose issues such as childhood abuse, rape and domestic violence to strangers, or felt treatment offered no benefits. Despite often complex ongoing mental health and addiction problems some did not want help.

- Current data support previous findings that this population have high rates of mental health problems, often unrecognised and untreated.Those who were in prison MBUs have better psycho-social outcomes than those separated from their children in prison

- Under 20% of separated mothers had care of their children at follow up, suggesting more needs to be done to help them remain together or reunite on release, if possible, particularly those caring for their children before prison

- GP data on children suggest a higher incidence of problems than the SDQ and poor agreement between the two suggesting mothers underestimated problems at interview

- Poor agreement between the research diagnosis of mental disorder and GP diagnosis, supports previous findings of poor identification of mental disorders by services

- Pregnant women in prison may not receive the same quality of NHS care as women in the community.This requires further investigation

- Mental health care in prison is experienced by women as inferior, and varies between establishments.Of particular concern is the almost universally poor continuity of mental health care between prison and community. Both prison and community services need to work collaboratively to improve transfer of mental health care for this particularly vulnerable group

- Prison MBUs are supportive environments and may impact on a range of psychosocial outcomes including re-offending.This requires further research

- Lack of accommodation on release needs addressed. It is vital in terms of stability, access to healthcare and preventing future re-offending

Patient and public involvement

We had 3 service users who attended meetings during the course of the study, either in person or by phone. Depending on personal circumstances they attended on one or more occasions. Their opinions and experiences were invaluable to the progress of the study. They were initially consulted at the planning stage, and asked to examine and comment on the original proposal prior to submission to the funding body. Some of the women were still in prison at the time of this consultation, and one was in prison for the duration of the project, but was able to attend some of the meetings by phone. Comments made by the mothers who had spent time in prison were incorporated into the final report, including on ways in which to contact/approach mothers to request participation in the follow up study.

When we found recruitment to be more difficult than anticipated, we discussed this issue with the service users whose advice was extremely useful. They helped identify reasons why some women did not respond, or did not wish to participate and suggested ways in which this might be addressed, but also helped us understand that for some women, particularly those with substance misuse problems, and/or those who no longer had care of their children, the reasons we might never get a response from them. They also reminded us that whilst sample size is an important factor in the validity of studies such as this, there are complex and very individual reasons specific to this population that could have a serious impact on recruitment.

We presented some early findings at a meeting of the prison MBU managers in 2011 and the results were presented and discussed at the meeting . The managers of the MBUs were very interested in the early findings, and the impact of the personal experience of a prisoner and a mother, involved in the study gave the findings a personal and human impact, which engaged the prison staff in lively discussion on how they could respond for the benefit of women in the future.

We plan to involve service users in the further dissemination of results, including presentations and papers over the next 12 months, and hope to be able to collate responses from stakeholders on actions that could be implemented to improve outcomes for these women and their children.

Data sharing statement

See link [https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Disclaimer

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This final report has not been peer-reviewed. The report was examined by the Programme Director at the time of submission to assess completeness against the stated aims.