

Mental health-related stigma and pathways to care for people at-risk of psychotic disorders or experiencing first-episode psychosis: systematic review

Petra Grönholm, PhD



HSPRD, Institute of Psychiatry, Psychology & Neuroscience,
King's College London

PSSRU, London School of Economics and Political Science

p.c.gronholm@lse.ac.uk

Overcoming Barriers in Mind
and Society - Together Against
Stigma 8th Conference

22/09/2017

KING'S
College
LONDON

Full paper available online!

Gronholm, P. C., Thornicroft, G., Laurens, K. R., & Evans-Lacko, S. (2017). Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: systematic review. *Psychological Medicine*, 47(111), 1867–1879. <https://doi.org/doi:10.1017/S0033291717000344>

Psychological Medicine, Page 1 of 13. © Cambridge University Press 2017
doi:10.1017/S0033291717000344

REVIEW ARTICLE

Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: a systematic review

P. C. Gronholm^{1*}, G. Thornicroft^{1,2,3}, K. R. Laurens^{4,5,6,7} and S. Evans-Lacko^{1,2,8}

¹ Health Service and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

² Centre for Global Mental Health, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

³ Centre for Implementation Science, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

⁴ Department of Forensic and Neurodevelopmental Science, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

⁵ School of Psychiatry, University of New South Wales, Sydney, New South Wales, Australia

⁶ Schizophrenia Research Institute, Sydney, New South Wales, Australia

⁷ Neuroscience Research Australia, Sydney, New South Wales, Australia

⁸ Personal Social Services Research Unit, London School of Economics and Political Science, London, UK

Background & aims

- Early intervention beneficial for psychotic disorders
- Stigma can delay or prevent help-seeking and service contact
- Stigma-related influences on pathways to care (PTC) in the early stages of psychotic disorders have not been systematically examined

- **Review aim:** Synthesise evidence on the relationship between stigma and pathways to care in early psychosis
 - ✓ *Primary objective:* examine stigma and PTC amongst people experiencing FEP/at-risk of psychotic disorder
 - ✓ *Secondary objectives:* 1) Mechanisms? 2) How well researched is this area?

Methods (1) – search strategy

Registered protocol (PROSPERO), followed PRISMA statement

Search strategy

1. Database search
 - CINAHL, EMBASE, Medline, PsycInfo, Sociological Abstracts
 - “at-risk status/FEP” AND “stigma” AND “help-seeking/service use”
2. Reference searches, citation searches
3. Expert recommendations

Methods (2) – inclusion criteria

Population

- First episode psychosis, symptoms indicating increased risk of developing psychotic disorder (aged \leq 40 years of age)

Domain

- *Stigma*: mental-health related stigma and/or discrimination
- *Pathways to care*: help-seeking processes/actions, service contact/use, periods of untreated illness
- *Person reporting on pathway*: person affected by FEP/at-risk stage, or significant other person assisting the affected person getting care (not professional)

Study type

- Data-based, peer-reviewed
- Qualitative, quantitative, mixed methods research

Other criteria

- Published Jan 1996 – July 2016; English language



Methods (3) – extraction & synthesis

Data extraction

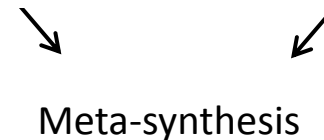
- Study design, population characteristics
- Summary descriptions of stigma and pathways to care, and their relationship

Methodological quality

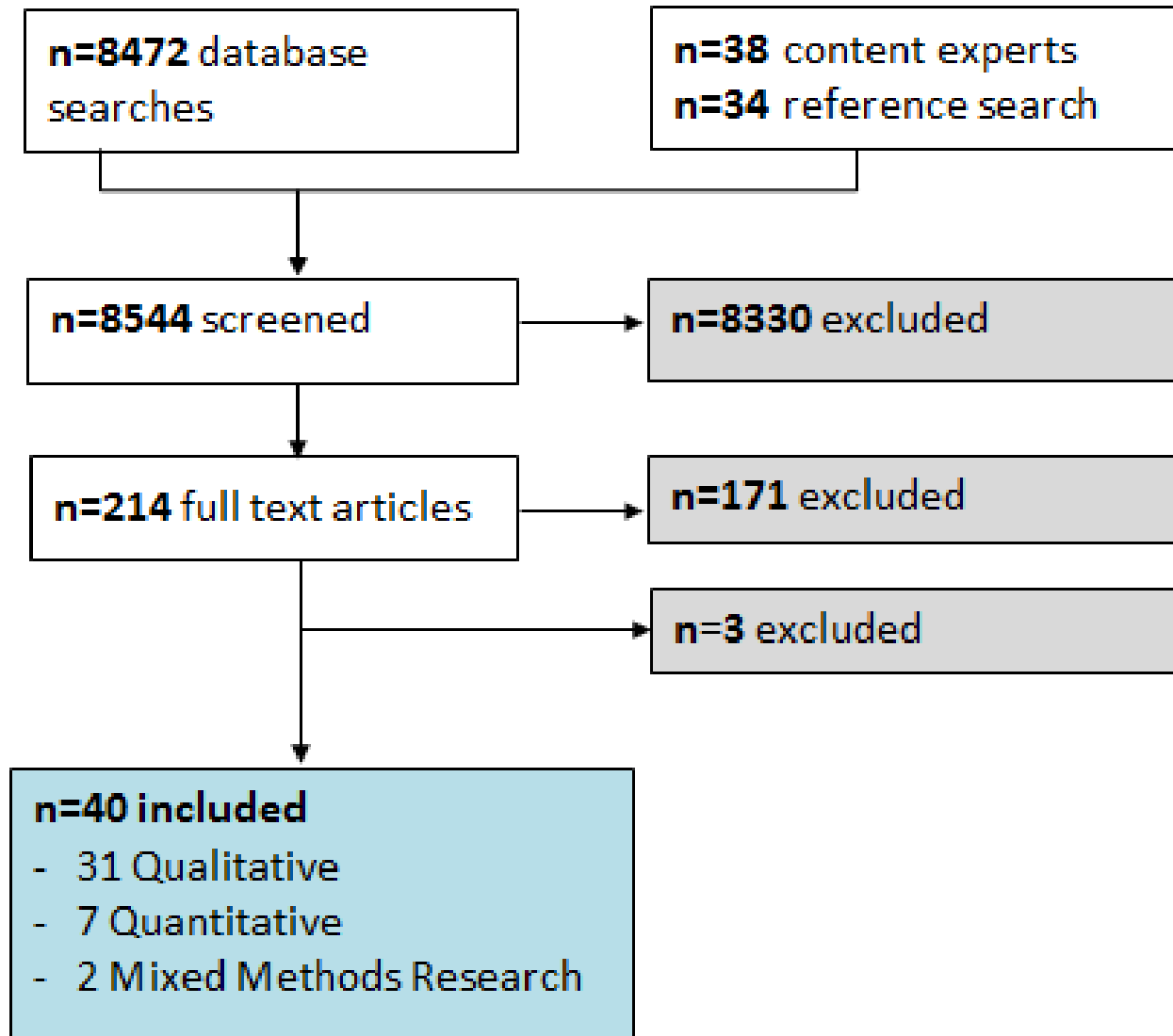
- Mixed Methods Appraisal Tool (MMAT; Pluye et al. 2011)
- Generic quality criteria + methodology specific criteria

Data synthesis

1. Qual: Thematic synthesis
2. Quant: Narrative synthesis
3. Combined through a meta-synthesis



Results (1) – study selection



Results (2) – study characteristics

Methodology

- Most qualitative: three-quarters (77.5%, 31/40)

Condition:

- FEP: Three-quarters (77.5%, 31/40)

Perspective/informant

- Affected person's own perspective: around half (55.0%, 22/40)
- Significant others: just under a third (30.0%, 12/40)
- Joint: rest (15.0%; 6/40)

Methodological quality

- ✓ Qualitative overall good: 87.1% (27/31) >50%;
- ✓ Quant more mixed; 50.0% most common (42.9%, 3/7).
- ✓ MMR poor (0.0% ; 37.5%)

Results (3) – QUAL thematic synthesis

33 articles (31 Qual, 2 MMR); n=541

1. **Sense of difference:** feeling different, not normal, something was “wrong”
2. **Characterising differences negatively:** difference labelled negatively, stereotyped beliefs (mad, crazy, mental, lazy, dangerous, incapable)
3. **Negative reactions (anticipated and experienced):** judgemental reactions, social distancing, shame or embarrassment, guilt, burdening/worrying others
4. **Strategies** to avoid the reactions; e.g. non-disclosure, concealment, denying/ignoring, normalising/rationalising
5. **Lack of knowledge and understanding:** stigma contributed towards limited awareness/understanding
6. **Service-related factors:** stigma linked to service context – stigmatising and de-stigmatising

Results (4) – QUANT narrative synthesis

9 articles (7 Quant, 2 MMR); n=692

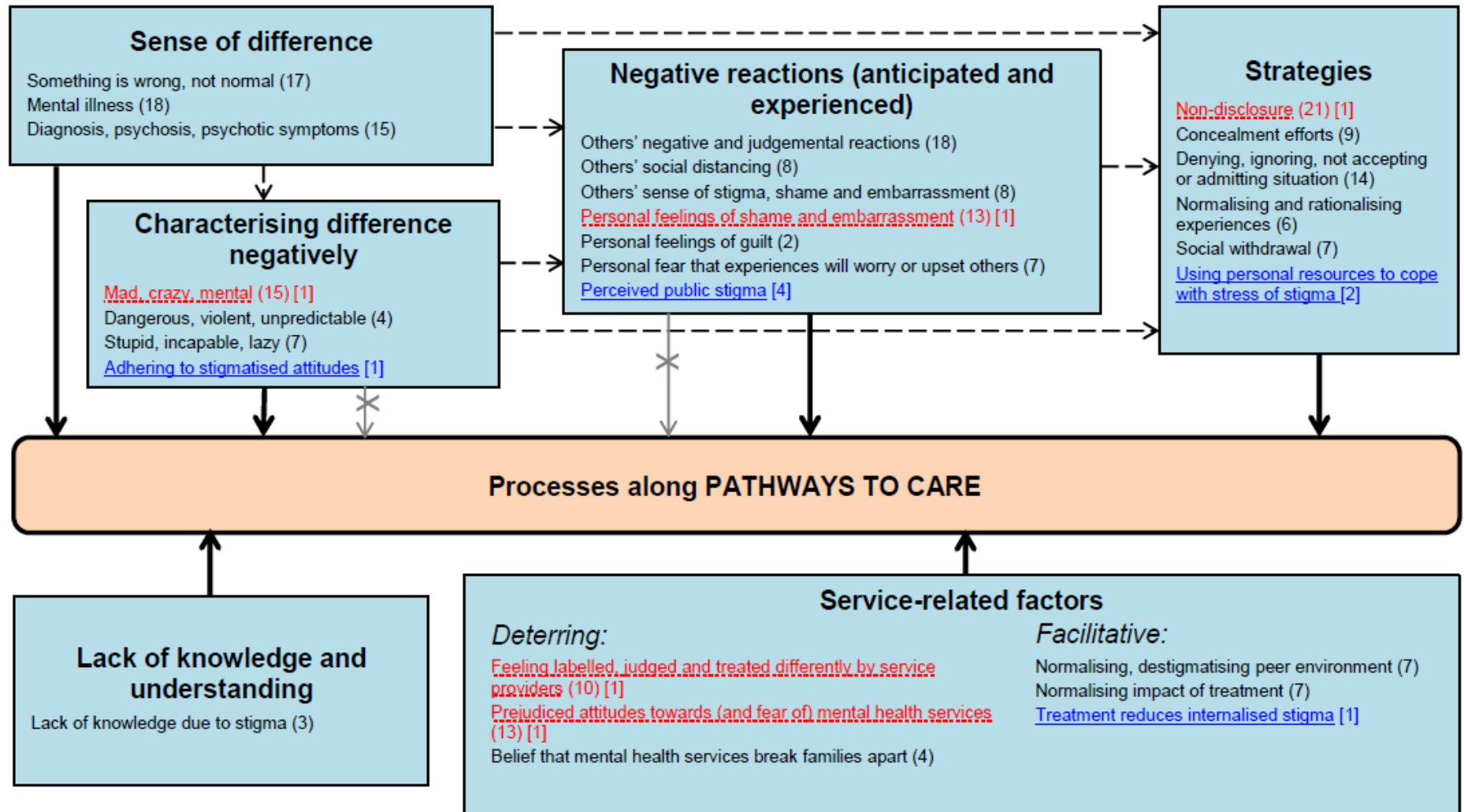
Association studies, n=6

- Multivariate, bivariate associations
- n=3 statistically significant
- Perceived stigma, stigma stress, stigmatised attitudes, internalised stigma
- E.g. lower stigma stress associated with more positive help-seeking attitudes (psychotherapy and psychiatric medication) ([Rüsch et al. 2013](#))

Descriptive studies, n=3

- Survey data on stigma-related experiences
- E.g. service-stigma a reason for opposing psychiatric treatment, shame main reason for non-disclosure of symptoms ([de Haan et al. 2002](#))

Results (5) – meta-synthesis



(Black = qual only; blue = quant only; red = both qual and quant)

Discussion (1)

- ✓ **Primary objective:** examine stigma and PTC amongst people experiencing FEP/at-risk of psychotic disorder
- Meta-synthesis >> six themes, conceptual model
- Complex relationship between stigma-related processes and elements on pathways to care
 - Multiple stigma-related concerns, fears, processes
 - PTC: stages of illness recognition, use of informal resources, help-seeking, service contact

Discussion (2)

✓ Secondary objectives

1) Mechanisms through which stigma influences PTC?

- Interconnections in conceptual model
- e.g. sense of difference -> anticipated labelling /judgemental reactions; strategies like concealment to avoid negative reactions

2) How well researched is this area?

- Qualitative, good; Quantitative, mixed; MMR, poor
- Research gaps:
 - No studies on stigma amongst “significant others” in at-risk groups
 - Poor MMR evidence base
 - High-income settings only
 - Role of culture

Discussion (3)

Differences in qual and quant findings

- Narrative data, stigma a key barrier vs. quantitative evidence, less clear
- Easier to capture stigma using qualitative means, more nuanced?

Corroborate past evidence

- Comparable to reports of stigma from e.g. samples with established diagnoses/chronic illness

Implications for anti-stigma efforts

- “Sense of difference”, something is “wrong”, being “not normal”, feeling “weird” -> mental health awareness efforts?
- Caregiver-targeted anti-stigma strategies?
- Reduce barriers to help-seeking/service contact >> facilitate early intervention

Conclusions

First systematic review to examine stigma and pathways to care in early psychosis

- Comprehensive overview of evidence base
- Conceptual model of stigma:
 - Generate insights of stigma-related processes and influences in early psychosis specifically
 - Comparisons with past research extend understanding of stigma in relation to help-seeking
 - Provides foundation for future research?

Acknowledgements

- *PhD Funding:* National Institute for Health Research (NIHR) Mental Health Biomedical Research Centre (BRC) at South London and Maudsley NHS Foundation Trust and King's College London
- *PhD supervisors:* Dr Sara Evans-Lacko, Professor Sir Graham Thornicroft, Dr Kristin Laurens
- *Conference attendance:* This work is/was supported by a Postgraduate International Conference Travel Grant from the Foundation for the Sociology of Health and Illness.
- *Thank you for your attention!*

p.c.gronholm@lse.ac.uk



References

Gronholm, P. C., Thornicroft, G., Laurens, K. R., & Evans-Lacko, S. (2017). Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: systematic review. *Psychological Medicine*, *47*(111), 1867–1879.
<https://doi.org/doi:10.1017/S0033291717000344>

- **PROSPERO protocol**

http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014009206

- **Mixed Methods Appraisal Tool**

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O’Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews.

<http://mixedmethodsappraisaltoolpublic.pbworks.com>

Sensitivity analysis: methodological quality

- Do methodological weaker papers influenced findings?
- Removed $\leq 50\%$ MMAT >>>
 - 11 articles removed
 - (n=4(/31) qualitative, n=5(/7) quantitative, n=2(/2) MMR)

- All MMR studies removed
- All quant-only subthemes dropped
- But, overall synthesis model thematic structure did not change

Subgroup comparisons

Examined the relative proportions of articles reporting on stigma-related themes compared across the groups:

People At-risk vs. people FEP

- “sense of difference” theme overall more often in FEP papers, but subthemes within >> vague sense of “not being normal, something wrong” more common in at-risk papers, sense of difference due to “mental illness” more common in FEP papers.
- ALL (3) “lack of knowledge” studies from FEP groups
- similar proportion of studies reported on themes “characterising difference negatively”, “negative reactions”, and “strategies”

Affected people (FEP or at-risk) vs. “significant others”

- “sense of difference” and “characterising difference negatively” more common in affected person papers
- “lack of knowledge” ALL from significant other perspective
- similar proportions reported “negative reactions” and “strategies” themes

Significant others of At-risk vs. Significant others of people with FEP

- Planned, but no studies examined this

Limitations

- ✓ Strategy (terms & databases) might not have captured everything
- ✓ No grey literature (limit due to feasibility)
- ✓ Thematic synthesis primarily conducted by one researcher; bias? >> discussions with co-authors; inclusion of quotes for transparency
- ✓ Quantitative results: narrative synthesis only (too heterogeneous for statistical pooling)
- ✓ High income, Western settings only
- ✓ Stigma not the only barrier! Also structural/situational, financial barriers, perceived service need, perceived ineffectiveness of services, preference to cope on own