LEMBAR
HASIL PENILAIAN SEJAWAT SEBIDANG ATAU *PEER REVIEW*
KARYA ILMIAH: JURNAL ILMIAH

Judul Jurnal Ilmiah (Artikel) : Feasibility of preconception screening for Thalassaemia in Indonesia: Exploring the opinion of Javanese mothers

Penulis Jurnal Ilmiah : Costrie G. Widayanti, **Annastasia Ediati**, Moedrik Tamam, Sultana MH Faradz, Erik A. Sistermans, & Anne Marie C. Plass

Jumlah Penulis : 6 orang

Status Pengusul : Penulis ke-dua

Identitas Jurnal Ilmiah :
a. Nama Jurnal : Ethnicity & Health
b. ISSN : 1355-7858, 1465-3419
c. Volume, nomor, bulan, tahun : 16(4-5), 2011
d. Penerbit : Taylor & Francis
e. DOI artikel : 10.1080/13557858.2011.564607
f. Alamat web jurnal :

URL JURNAL: https://www.tandfonline.com/toc/ceth20/16/4-5?nav=tocList

URL ARTIKEL: https://doc-pak.undip.ac.id/id/eprint/17071

g. Terindeks di Scopus/Scimagojr/SJR: 0,854 (2017) dan Q1

Kategori Publikasi Jurnal Ilmiah (beri ✓pada kategori yang tepat) :
☑ Jurnal Ilmiah Internasional Bereputasi
☐ Jurnal Ilmiah Internasional
☐ Jurnal Ilmiah Nasional Terakreditasi
☐ Jurnal Ilmiah Nasional Tidak Terakreditasi
☐ Jurnal Ilmiah Nasional Terindeks DOAJ, dll

Hasil Penilaian *Peer Review*:

Komponen yang Dinilai	Nilai Maksimal [40		Nilai Rata-Rata
	Reviewer 1	Reviewer 2	
a. Kelengkapan unsur isi artikel (10%)	4	4	4,0
b. Ruang lingkup dan kedalaman pembahasan (30%)	12	10	11,0
c. Kecukupan dan kemutahiran data/ informasi dan metodologi (30%)	12	10	11,0
d. Kelengkapan unsur dan kualitas penerbit (30%)	12	12	12,0
Total = (100%)	40	36	38,0
Skor yang diperoleh = (40% x nilai total) / 5	**3,2**	**2,88**	**3,04**

Semarang, 8 November 2018

Reviewer 1 — Prof. Johana Endang Prawitasari, Ph.D
NIDK. 8818240017 ……

Reviewer 2 — Prof. Dr. Tina Afiatin, M.Si., Psikolog
NIP. 196402111989032003 ……

LEMBAR
HASIL PENILAIAN SEJAWAT SEBIDANG ATAU *PEER REVIEW*
KARYA ILMIAH: JURNAL ILMIAH

Judul Jurnal Ilmiah (Artikel) : Feasibility of preconception screening for Thalassaemia in Indonesia: Exploring the opinion of Javanese mothers
Penulis Jurnal Ilmiah : Costrie G. Widayanti, **Annastasia Ediati** , Moedrik Tamam, Sultana MH Faradz, Erik A. Sistermans, & Anne Marie C. Plass
Jumlah Penulis : 6 orang
Status Pengusul : Penulis ke-dua
Identitas Jurnal Ilmiah :
a. Nama Jurnal : Ethnicity & Health
b. ISSN : 1355-7858, 1465-3419
c. Volume, nomor, bulan, tahun : 16(4-5), 2011
d. Penerbit : Taylor & Francis
e. DOI artikel (jika ada) : 10.1080/13557858.2011.564607
f. Alamat web jurnal :
JURNAL: https://www.tandfonline.com/toc/ceth20/16/4-5?nav=tocList
ARTIKEL: https://doc-pak.undip.ac.id/id/eprint/17071
g. Terindeks di Scopus/Scimagojr/SJR: 0,854 (2017) dan Q1

Kategori Publikasi Jurnal Ilmiah (beri ✓pada kategori yang tepat) :
☑ Jurnal Ilmiah Internasional Bereputasi
☐ Jurnal Ilmiah Internasional
☐ Jurnal Ilmiah Nasional Terakreditasi
☐ Jurnal Ilmiah Nasional Tidak Terakreditasi
☐ Jurnal Ilmiah Nasional Terindeks DOAJ, dll

Hasil Penilaian *Peer Review* :

Komponen yang Dinilai	Nilai Maksimal Jurnal Ilmiah					Nilai yang Diperoleh
	Internasional Bereputasi [40]	Internasional	Nasional Terakreditasi	Nasional Tidak Terakreditasi	Nasional Terindeks DOAJ	
a. Kelengkapan unsur isi artikel (10%)	4,00					4
b. Ruang lingkup dan kedalaman pembahasan (30%)	12,00					12
c. Kecukupan dan kemutahiran data/ informasi dan metodologi (30%)	12,00					12
d. Kelengkapan unsur dan kualitas penerbit (30%)	12,00					12
Total = (100%)	40,00					40
Nilai Pengusul = (40% x 40) / 5 = 3,2						

Catatan Penilaian Artikel oleh Reviewer

1. **Kesesuaian dan kelengkapan unsur isi jurnal**:
Struktur penulisan lengkap sesuai dengan kaidah penulisan ilmiah di bidang psikologi dan panduan penulisan yang disediakan oleh jurnal *Ethinicity & Health*, yakni terdiri dari *Abstract, Introduction,*

Method (Design, Participants and Procedure, Measures, Data Analysis), Results, Discussion, Limitation of study, Key messages, Acknowledgement, dan *References.*

2. **Ruang lingkup dan kedalaman pembahasan**:
   Ruang lingkup pembahasan artikel sesuai dengan ruang lingkup jurnal, yakni mengenai persepsi ibu yang memiliki anak dengan Thalasemia. Pembahasan mendalam dengan mengacu pada *Theory of Planned Behavior* yang dikembangkan Ajzen. Disamping itu, artikel ini juga mengulas hasil-hasil penelitian sebelumnya, baik di bagian pendahuluan maupun pembahasan (diskusi), serta keterbatasan penelitian ini.

3. **Kecukupan dan kemutakhiran data/informasi dan metodologi**:
   Artikel ini mengutip 31 referensi yang relevan dengan tulisan mengenai thalassemia dan 87% diantaranya (27 referensi) merupakan referensi yang mutakhir. Metode penelitian yang digunakan untuk mengungkap persepsi ibu yang memiliki anak dengan thalassemia dipandang cukup memadai, yakni menggunakan pendekatan kuantitatif yang menggunakan skala pengukuran psikologi yang sesuai dengan kaidah psikometri.

4. **Kelengkapan unsur dan kualitas terbitan**: Jurnal ini tergolong Jurnal Internasional Bereputasi (Editorial board lebih dari 4 negara, contributor lebih dari 2 negara, ISSN 1355-7858 (print) / 1465-3419 (online), terindeks di Scopus, SJR 0,854 (2017)/Q1, Impact factor 1,766 (2017).

Jakarta, 29 Oktober 2018
Reviewer 1,

Prof. Johana Endang Prawitasari, Ph.D
NIDK. 8818240017
Unit kerja : Fakultas Psikologi
Universitas Kristen Krida Wacana, Jakarta
Bidang Ilmu: Psikologi Klinis

LEMBAR
HASIL PENILAIAN SEJAWAT SEBIDANG ATAU *PEER REVIEW*
KARYA ILMIAH: JURNAL ILMIAH

Judul Jurnal Ilmiah (Artikel) : Feasibility of preconception screening for Thalassaemia in Indonesia: Exploring the opinion of Javanese mothers
Penulis Jurnal Ilmiah : Costrie G. Widayanti, **Annastasia Ediati** , Moedrik Tamam, Sultana MH Faradz, Erik A. Sistermans, & Anne Marie C. Plass
Jumlah Penulis : 6 orang
Status Pengusul : Penulis ke-dua
Identitas Jurnal Ilmiah :
a. Nama Jurnal : Ethnicity & Health
b. ISSN : 1355-7858, 1465-3419
c. Volume, nomor, bulan, tahun : 16(4-5), 2011
d. Penerbit : Taylor & Francis
e. DOI artikel : 10.1080/13557858.2011.564607
f. Alamat web jurnal :
URL JURNAL: https://www.tandfonline.com/toc/ceth20/16/4-5?nav=tocList
URL ARTIKEL: https://doc-pak.undip.ac.id/id/eprint/17071
g. Terindeks di Scopus/Scimagojr/SJR: 0,854 (2017) dan Q1

Kategori Publikasi Jurnal Ilmiah (beri ✓pada kategori yang tepat) :
☑ Jurnal Ilmiah Internasional Bereputasi
☐ Jurnal Ilmiah Internasional
☐ Jurnal Ilmiah Nasional Terakreditasi
☐ Jurnal Ilmiah Nasional Tidak Terakreditasi
☐ Jurnal Ilmiah Nasional Terindeks DOAJ, dll

Hasil Penilaian *Peer Review* :

Komponen yang Dinilai	Nilai Maksimal Jurnal Ilmiah					Nilai yang Diperoleh
	Internasional Bereputasi [40]	Internasional	Nasional Terakreditasi	Nasional Tidak Terakreditasi	Nasional Terindeks DOAJ	
a. Kelengkapan unsur isi artikel (10%)	4,00					4
b. Ruang lingkup dan kedalaman pembahasan (30%)	12,00					10
c. Kecukupan dan kemutahiran data/ informasi dan metodologi (30%)	12,00					10
d. Kelengkapan unsur dan kualitas penerbit (30%)	12,00					12
Total = (100%)	40,00					36
Nilai Pengusul = (40% x 36)/5 = 14,4/5 = 2,88						**2,88**

Catatan Penilaian Artikel oleh Reviewer

1. **Kesesuaian dan kelengkapan unsur isi jurnal**:
Penulisan artikel sudah sesuai dengan *Instruction for Authors* (*Title, Abstract, Introduction, Methods, Results, Discussion, Acknowledgements, References*) dengan gaya selingkung APA. Substansi artikel sesuai dengan bidang ilmu pengusul (Ilmu Psikologi). Ada benang merah dalam struktur penulisannya

2. **Ruang lingkup dan kedalaman pembahasan**:
   - Tidak ada penjelasan tentang justifikasi pentingnya meneliti variabel attitude toward carrier testing for thalassaemia, social norms concerning carrier testing for Thalassemia, perceived behavioral control over carrier testing for thalassaemia, dan attitude towards receiving information about thalassaemia.

3. **Kecukupan dan kemutakhiran data/informasi dan metodologi**
   - Tidak ada penjelasan prosedur uji coba alat ukur dan penjelasan rinci tentang kualitas alat ukur (validitas dan reliabilitas).
   - Data penelitian bersifat *non probability sample* sehingga tidak dapat digeneralisasi untuk populasi di Indonesia.

4. **Kelengkapan unsur dan kualitas terbitan**:
   - tergolong Jurnal Internasional Bereputasi
   - Dewan Editor lebih dari 4 negara
   - penulis kontributor lebih dari 2 negara
   - terindeks di Scopus
   - SJR 0,854 (2017)/Q1
   - Impact factor 1,766 (2017)

Yogyakarta, 29 Oktober 2018
Reviewer 2,

Prof. Dr. Tina Afiatin, M.Si., Psikolog
NIP. 196402111989032003
Unit kerja : Fakultas Psikologi
Universitas Gadjah Mada, Yogyakarta
Bidang Ilmu: Psikologi

Ethnicity and Health • *Open Access* • Volume 16, Issue 4-5, Pages 483 - 499 • August 2011

Document type
Article • *Green Open Access*

Source type
Journal

ISSN
14653419

DOI
10.1080/13557858.2011.564607

View more

Feasibility of preconception screening for thalassaemia in Indonesia: Exploring the opinion of Javanese mothers

Widayanti, Costrie Ganes[a, b]; Ediati, Annastasia[b, c]; Tamam, Moedrik[d]; Faradz, Sultana M. H.[c]; Sistermans, Erik A.[e]; Plass, Anne Marie C.[e, f]

Save all to author list

[a] Biomedical Postgraduate Program on Genetic Counseling, Faculty of Medicine, Diponegoro University, Semarang, Indonesia

[b] Faculty of Psychology, Diponegoro University, Semarang, Indonesia

[c] Centre for Biomedical Research (CEBIOR), Faculty of Medicine, Diponegoro University, Semarang, Indonesia

[d] Department of Paediatrics, Diponegoro University, Dr. Kariadi Hospital, Semarang, Indonesia

View additional affiliations

Abstract

Background. Thalassaemia has become a major public health issue in Indonesia. It has been estimated that up to 10% of the population carries a gene associated with beta-thalassaemia. Currently, there is no formal recommendation for thalassaemia screening. This study aimed to explore awareness of thalassaemia, and to explore attitudes regarding carrier testing among Javanese mothers. Methods. A

Related documents

The attitudes and intention to participate in hemoglobinopathy carrier screening in the Netherlands among individuals from turkish, moroccan, and surinamese descent

Van Der Pal, S.M. , Van Kesteren, N.M.C. , Van Wouwe, J.P.
(2013) Journal of Environmental and Public Health

Preconception carrier screening for multiple disorders: Evaluation of a screening offer in a Dutch founder population /631/208/2489/1512 /692/700/478/2772 article

Mathijssen, I.B. , Holtkamp, K.C.A. , Ottenheim, C.P.E.
(2018) European Journal of Human Genetics

Preconceptional ancestry-based carrier couple screening for cystic fibrosis and haemoglobinopathies: What determines the intention to participate or not and actual participation?

Lakeman, P. , Plass, A.M.C. , Henneman, L.

quantitative questionnaire, designed using constructs of the Theory of Planned Behaviour, was applied cross-sectionally. Results. Out of 191 mothers who were invited, 180 agreed to participate (RR = 94%), of whom 74 had a child affected with thalassaemia. Both attitudes towards receiving information about thalassaemia, and attitudes towards carrier testing were very positive. Awareness of thalassaemia was poor. Mothers, both those with and without an affected child, had barely heard of thalassaemia, nor of carrier testing. However, all mothers, including those with an affected child expressed high levels of interest in carrier testing. Respondents did not perceive that they had any control over carrier testing, and feared stigmatization and being discriminated against if their carrier status was identified. Attitudes towards carrier testing explained 23% of future reproductive intentions, in addition to perceived stigmatization, education level and 'mother's age' (R2=0.44; p=0.001). Conclusion. Responding mothers expressed high levels of interest in receiving information on both thalassaemia and carrier testing. The less educated and the more deprived they were, the keener they were to receive this information. Overall, awareness of thalassaemia was low. Even mothers with affected children seemed unaware of the inheritance pattern and the recurrent risk of having an affected child in a subsequent pregnancy, showing the need for genetic counselling in Indonesia. It is therefore recommended not only to raise awareness about thalassaemia, but to improve the education of healthcare professionals as well. © 2011 Taylor & Francis.

Author keywords

awareness; carrier screening; genetic awareness; Indonesia; Javanese mothers; thalassaemia; Theory of Planned Behaviour (TpB)

Indexed keywords

Sustainable Development Goals 2022 New

SciVal Topics

Metrics

References (31)

View in search results format >

All

Export Print E-mail Save to PDF Create bibliography

1 Ahmed, S., Bekker, H., Hewison, J., Kinsey, S.

Thalassaemia carrier testing in Pakistani adults: Behaviour, knowledge and attitudes

(2002) *Community Genetics*, 5 (2), pp. 120-127. Cited 18 times.
doi: 10.1159/000065167

View at Publisher

2 Ahmed, S., Green, J.M., Hewison, J.

Attitudes towards prenatal diagnosis and termination of pregnancy for thalassaemia in pregnant Pakistani women in the North of England

(2006) *Prenatal Diagnosis*, 26 (3), pp. 248-257. Cited 57 times.
doi: 10.1002/pd.1391

View at Publisher

3 Ajzen, I.

The theory of planned behavior

(1991) *Organizational Behavior and Human Decision Processes*, 50 (2), pp. 179-211. Cited 47174 times.
doi: 10.1016/0749-5978(91)90020-T

View at Publisher

(2009) European Journal of Human Genetics
View all related documents based on references

Find more related documents in Scopus based on:

Authors > Keywords >

4 Albert, I.
Value of children in urban and rural Indonesia: Socio demographics indicators, cultural aspects, and empirical findings
(2005) *The Value of Children in Cross-Cultural Perspective*, pp. 171-207. Cited 19 times.
In: G. Trommelsdorf and B. Nauck, eds., Lengerich: Pabst Science Publishers

5 Beale, D.A., Manstead, A.S.R.
Predicting Mothers' Intentions to Limit Frequency of Infants' Sugar Intake: Testing the Theory of Planned Behavior
(1991) *Journal of Applied Social Psychology*, 21 (5), pp. 409-431. Cited 109 times.
doi: 10.1111/j.1559-1816.1991.tb00528.x
View at Publisher

6 Bottorff, J.L., Ratner, P.A., Balneaves, L.G., Richardson, C.G., Buxton, J., McCullum, M., Hack, T., (...), Chalmers, K.
Women's interest in genetic testing for breast cancer risk: The influence of sociodemographics and knowledge
(2002) *Cancer Epidemiology Biomarkers and Prevention*, 11 (1), pp. 89-95. Cited 69 times.
View at Publisher

7 (2006) *National Economic Survey, Statistics of Jawa Tengah Province [online]*
BPS, Available from
http://jateng.bps.go.id/2006/web06bab103/103popu_eng.html

8 Burnes, D.P.R., Antle, B.J., Williams, C.C., Cook, L.
Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma
(2008) *Health and Social Work*, 33 (3), pp. 211-220. Cited 48 times.
http://hsw.oxfordjournals.org/content/by/year
doi: 10.1093/hsw/33.3.211
View at Publisher

9 Dhamcharee, V., Romyanan, O., Ninlagarn, T.
Genetic counseling for thalassemia in Thailand : Problems and solution
(2001) *Southeast Asian Journal of Tropical Medicine and Public Health*, 32 (2), pp. 413-418. Cited 13 times.
http://www.tm.mahidol.ac.th/seameo/publication.htmhttps://seameotropmednetwork.org/publication_current_issue.html

10 Frost, S., Myers, L.B., Newman, S.P.
Genetic screening for Alzheimer's disease: What factors predict intentions to take a test
(2001) *Behavioral Medicine*, 27 (3), pp. 101-109. Cited 43 times.
doi: 10.1080/08964280109595776
View at Publisher

11 Henneman, L., Bramsen, I., Van der Ploeg, H.M., Adèr, H.J., Van der Horst, H.E., Gille, J.J.P., Ten Kate, L.P.

Participation in preconceptional carrier couple screening: Characteristics, attitudes, and knowledge of both partners [3]

(2001) *Journal of Medical Genetics*, 38 (10), pp. 695-703. Cited 53 times.

View at Publisher

12 Kreuter, M.W.

Dealing with competing and conflicting risks in cancer communication. (Open Access)

(1999) *Journal of the National Cancer Institute. Monographs*, (25), pp. 27-35. Cited 38 times.
doi: 10.1093/oxfordjournals.jncimonographs.a024203

View at Publisher

13 Lakeman, P., Plass, A.M.C., Henneman, L., Bezemer, P.D., Cornel, M.C., Ten Kate, L.P.

Three-month follow-up of Western and non-Western participants in a study on preconceptional ancestry-based carrier couple screening for cystic fibrosis and hemoglobinopathies in the Netherlands (Open Access)

(2008) *Genetics in Medicine*, 10 (11), pp. 820-830. Cited 47 times.
doi: 10.1097/GIM.0b013e318188d04c

View at Publisher

14 Lakeman, P., Plass, A.M.C., Henneman, L., Bezemer, P.D., Cornel, M.C., ten Kate, L.P.

Preconceptional ancestry-based carrier couple screening for cystic fibrosis and haemoglobinopathies: What determines the intention to participate or not and actual participation? (Open Access)

(2009) *European Journal of Human Genetics*, 17 (8), pp. 999-1009. Cited 35 times.
doi: 10.1038/ejhg.2009.1

View at Publisher

15 Martens, S.
Invisible women: Gender, genetics and reproduction
(2002) *The Double-Edged Helix: Social Implications of Genetics in a Diverse Society*. Cited 4 times.
In: J.S. Alper et al., eds., Baltimore: The John Hopkins, University Press, 102-122

16 Meiser, B., Eisenbruch, M., Barlow-Stewart, K., Tucker, K., Steel, Z., Goldstein, D.

Cultural aspects of cancer genetics: Setting a research agenda (Open Access)

(2001) *Journal of Medical Genetics*, 38 (7), pp. 425-429. Cited 40 times.
http://jmg.bmj.com/content/by/year
doi: 10.1136/jmg.38.7.425

View at Publisher

17 Modell, B., Darlison, M.
Global epidemiology of haemoglobin disorders and derived service indicators (Open Access)

(2008) *Bulletin of the World Health Organization*, 86 (6), pp. 480-487. Cited 1124 times.
http://www.who.int/entity/bulletin/volumes/86/6/06-036673.pdf
doi: 10.2471/BLT.06.036673

View at Publisher

18 Plass, A.M.C., Van El, C.G., Pieters, T., Cornel, M.C.
Neonatal screening for treatable and untreatable disorders: Prospective parents' opinions

(2010) *Pediatrics*, 125 (1), pp. e99-e106. Cited 40 times.
http://pediatrics.aappublications.org/cgi/reprint/125/1/e99
doi: 10.1542/peds.2009-0269

View at Publisher

19 Poppelaars, F.A.M., Henneman, L., Adèr, H.J., Cornel, M.C., Hermens, R.P.M.G., Van Der Wal, G., Ten Kate, L.P.
Preconceptional cystic fibrosis carrier screening: Attitudes and intentions of the target population (Open Access)

(2004) *Genetic Testing*, 8 (2), pp. 80-89. Cited 31 times.
doi: 10.1089/gte.2004.8.80

View at Publisher

20 Pramoonjago, P., Harahap, A., Taufani, R.A., Setianingsih, I., Marzuki, S.
Rapid screening for the most common β thalassaemia mutations in south east Asia by PCR based restriction fragment length polymorphism analysis (PCR-RFLP) [6]

(1999) *Journal of Medical Genetics*, 36 (12), pp. 937-938. Cited 7 times.

View at Publisher

21 Prentice, K.J., Gold, J.M., Carpenter Jr., W.T.
Optimistic bias in the perception of personal risk: Patterns in schizophrenia

(2005) *American Journal of Psychiatry*, 162 (3), pp. 507-512. Cited 37 times.
doi: 10.1176/appi.ajp.162.3.507

View at Publisher

22 Samavat, A., Modell, B.
Iranian national thalassaemia screening programme (Open Access)

(2004) *British Medical Journal*, 329 (7475), pp. 1134-1137. Cited 209 times.
http://www.bmj.com/
doi: 10.1136/bmj.329.7475.1134

View at Publisher

23 Setianingsih, I., Williamson, R., Marzuk, S., Harahap, A., Tamam, M., Forrest, S.
Molecular basis of β-thalassemia in indonesia: Application to prenatal diagnosis

(1998) *Molecular Diagnosis*, 3 (1), pp. 11-20. Cited 23 times.
http://www.ingentaconnect.com
doi: 10.1016/S1084-8592(98)80022-2

View at Publisher

24 Shiloh, S., Reznik, H., Bat-Miriam-Katznelson, M., Goldman, B.
Pre-marital genetic counselling to consanguineous couples: Attitudes, beliefs and decisions among counselled, noncounselled and unrelated couples in Israel

(1995) *Social Science and Medicine*, 41 (9), pp. 1301-1310. Cited 38 times.
doi: 10.1016/0277-9536(94)00433-T

View at Publisher

25 Timan, I.S., Aulia, D., Atmakusma, D., Sudoyo, A., Windiastuti, E., Kosasih, A.
Some hematological problems in Indonesia.

(2002) *International journal of hematology*, 76 Suppl 1, pp. 286-290. Cited 12 times.
doi: 10.1007/BF03165264

View at Publisher

26 (2010) *Indonesia Statistics*. Cited 4 times.
UNICEF, [online].Available from
http://www.unicef.org/infobycountry/indonesia_statistics.html

27 Wahidiyat, I., Wahidiyat, P.A.
Genetic problems at present and their challenges in the future: Thalassemia as a model
(2006) *Paediatrica Indonesia*, 46 (9-10), pp. 189-194. Cited 3 times.

28 Weinreich, S.S., De Lange-De Klerk, E.S., Rijmen, F., Cornel, M.C., De Kinderen, M., Plass, A.M.C.
Raising awareness of carrier testing for hereditary haemoglobinopathies in high-risk ethnic groups in the Netherlands: A pilot study among the general public and primary care providers (Open Access)

(2009) *BMC Public Health*, 9, art. no. 338. Cited 19 times.
doi: 10.1186/1471-2458-9-338

View at Publisher

29 (2006) *Sickle-Cell Anaemia*. Cited 148 times.
WHO, World Health Organisation [online]. Available from
http://www.who.int/gb/ebwha/pdf-files/WHA59/A59-9-en.pdf

30 (2006) *Thalassaemia and Other Haemoglobinopaties*. Cited 13 times.
WHO, World Health Organisation [online].Available from
http://www.who.int/gb/ebwha/pdf-files/EB118/B118-5-en.pdf

31 Zevalkink, J., Riksen-Walraven, J.M.
Parenting in Indonesia: Inter- and intracultural differences in mothers' interactions with their young children

(2001) *International Journal of Behavioral Development*, 25 (2), pp. 167-175. Cited 35 times.
doi: 10.1080/01650250042000113

View at Publisher

Plass, A.M.C.; Department of Clinical Genetics, VU University Medical Center, Netherlands; email:anne.marie.plass@kpnmail.nl

About Scopus

What is Scopus

Content coverage

Scopus blog

Scopus API

Privacy matters

Language

日本語版を表示する

查看简体中文版本

查看繁體中文版本

Просмотр версии на русском языке

Customer Service

Help

Tutorials

Contact us

Source details

Ethnicity and Health

Scopus coverage years: from 1996 to Present

Publisher: Taylor & Francis

ISSN: 1355-7858 E-ISSN: 1465-3419

Subject area: Social Sciences: Cultural Studies | Arts and Humanities: Arts and Humanities (miscellaneous) | Medicine: Public Health, Environmental and Occupational Health

Source type: Journal

CiteScore 2021
4.4

SJR 2021
0.654

SNIP 2021
1.022

View all documents > | Set document alert | Save to source list | Source Homepage

CiteScore | CiteScore rank & trend | Scopus content coverage

Improved CiteScore methodology

CiteScore 2021 counts the citations received in 2018-2021 to articles, reviews, conference papers, book chapters and data papers published in 2018-2021, and divides this by the number of publications published in 2018-2021. Learn more >

CiteScore 2021

$$4.4 = \frac{1{,}237 \text{ Citations 2018 - 2021}}{281 \text{ Documents 2018 - 2021}}$$

Calculated on 05 May, 2022

CiteScoreTracker 2022

$$5.2 = \frac{1{,}739 \text{ Citations to date}}{334 \text{ Documents to date}}$$

Last updated on 05 April, 2023 • Updated monthly

CiteScore rank 2021

Category	Rank	Percentile
Social Sciences — Cultural Studies	#22/1127	98th
Arts and Humanities — Arts and Humanities (miscellaneous)	#57/376	84th
Medicine		

View CiteScore methodology > | CiteScore FAQ > | Add CiteScore to your site

About Scopus

What is Scopus

Content coverage

Scopus blog

Scopus API

Privacy matters

Language

日本語版を表示する

查看简体中文版本

查看繁體中文版本

Просмотр версии на русском языке

Customer Service

Help

Tutorials

Contact us

Ethnicity and Health

COUNTRY

United Kingdom

Universities and research institutions in United Kingdom

Media Ranking in United Kingdom

SUBJECT AREA AND CATEGORY

Arts and Humanities
- Arts and Humanities (miscellaneous)

Medicine
- Public Health, Environmental and Occupational Health

Social Sciences
- Cultural Studies

PUBLISHER

Routledge

H-INDEX

60

PUBLICATION TYPE

Journals

ISSN

13557858, 14653419

COVERAGE

1996-2021

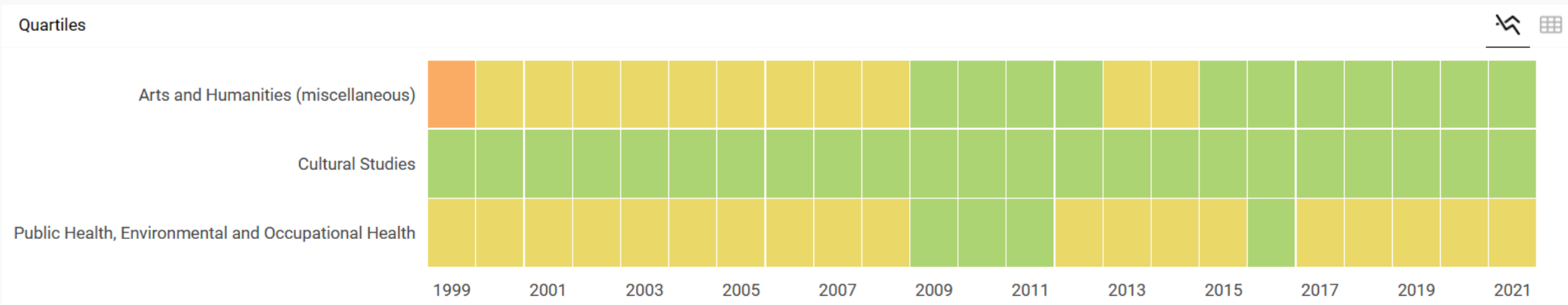
INFORMATION

Homepage

SCOPE

Ethnicity & Health is an international academic journal designed to meet the world-wide interest in the health of ethnic groups. It embraces original papers from the full range of disciplines concerned with investigating the relationship between "ethnicity" and "health" (including medicine and nursing, public health, epidemiology, social sciences, population sciences, and statistics). The journal also covers issues of culture, religion, gender, class, migration, lifestyle and racism, in so far as they relate to health and its anthropological and social aspects.

Join the conversation about this journal



Source details

Feedback > Compare sources >

Ethnicity and Health

Scopus coverage years: from 1996 to Present

Publisher: Taylor & Francis

ISSN: 1355-7858 E-ISSN: 1465-3419

Subject area: Social Sciences: Cultural Studies | Arts and Humanities: Arts and Humanities (miscellaneous) | Medicine: Public Health, Environmental and Occupational Health

Source type: Journal

View all documents > | Set document alert | Save to source list | Source Homepage

CiteScore 2021
4.4

SJR 2021
0.654

SNIP 2021
1.022

CiteScore CiteScore rank & trend Scopus content coverage

Ethnicity & Health

Publish open access in this journal

Publishes research exploring race and ethnic public health, medical, epidemiological, sociological, behavioral, psychological, and cultural issues.

@EthnicityHealth

@EthnicityHealth

Journal overview

Aims and scope

Journal metrics › | Editorial board ›

Instructions for authors ›

Open Access option available for this journal - Taylor & Francis Open Select

Ethnicity & Health is an international academic journal designed to meet the world-wide interest in the health of ethnic groups. It embraces original papers from the full

Read full aims and scope

Ethnicity & Health

and Spanish-speaking Latinas over 40 years of age in the United States: a analysis of the Behavioral Risk Factor Surveillance System ›

Avery Dutcher et al.

Article | Published online: 9 Apr 2023

Using the integrated theory of health behavior change to assess factors affecting diabetes medication adherence among black adults during COVID-19: an explanatory sequential mixed methods design ›

Deepika Rao et al.

Article | Published online: 8 Apr 2023

Vaccine perceptions among Black adults with long COVID ›

Samantha G. Dell'Imperio et al.

Article | Published online: 2 Apr 2023

Depression impairment among young adult college students: exploring the racial paradox ›

Hans Oh et al.

Brief Report | Published online: 30 Mar 2023

View all latest articles ›

Latest issues

Recent issues

List of issues › | Special issues ›

Current issue

Ethnicity & Health

Updates

Journal news & offers

Recruiting for Editorial Board Members and Peer Reviewers

Ethnicity & Health

Authors
R&D professionals
Overview
Open journals

Publish with us
Explore
Subscribe
Latest issue
+ Purchase a subscription

Opportunities

Reprints and e-prints
Advertising solutions
Accelerated publication
Corporate access solutions

Help and information

Help and contact
Newsroom
All journals
Books

Keep up to date

Register to receive personalised research and resources by email

Sign me up

Ready to submit?

Start a new manuscript submission or continue a submission in progress

Go to submission site

Submission information

- Instructions for authors
- Editorial policies

Editing services

- Editing services site

About this journal

- Journal metrics
- Aims & scope
- Journal information
- Editorial board
- News & call for papers
- Advertising information

Editorial board

Ethnicity & Health

Browse this journal
Latest articles
Current issue
List of issues
Special issues
Open access articles
Most read articles
Most cited articles

Ethnicity & Health, Volume 16, Issue 4-5 (2011)

See all volumes and issues

)12 | Volume 16, 2011 | Vol 15, 2010 | Vol 14, 2009 | \

e Issue 4-5 | Issue 3 | Issue 2 | Issue 1

Browse by section (All)
Display order (Default)

Download citations | Download PDFs | Download issue

Sickle cell and thalassaemia

Ethnicity & Health

Editorial

Sickle cell and thalassaemia: global public health issues come of age ›

1044 Views | 10 CrossRef citations | 1 Altmetric

Original Articles

Article

Informing choice or teaching submission to medical authority: a case study of adolescent transitioning for sickle cell patients ›

Carolyn Moxley Rouse

Pages: 313-325

Published online: 28 Jul 2011

477 Views | 6 CrossRef citations | 0 Altmetric

Article

'He's the dad isn't he?' Gender, race and the politics of prenatal screening ›

Kate Reed

Pages: 327-341

Published online: 28 Jul 2011

535 Views | 7 CrossRef citations | 0 Altmetric

Article

'All her children are born that way': gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya ›

Vicki M. Marsh, Dorcas M. Kamuya & Sassy S. Molyneux

Pages: 343-359

Published online: 28 Jul 2011

2294 Views | 69 CrossRef citations | 3 Altmetric

Article

Familial influences on antenatal and newborn haemoglobinopathy screening ›

Fiona Ulph, Tim Cullinan, Nadeem Qureshi & Joe Kai

Pages: 361-375

Published online: 28 Jul 2011

Ethnicity & Health

Pages: 377-388
Published online: 28 Jul 2011

Article

Living with sickle cell disease: traversing 'race' and identity ›

Charmaine D. Royal, Charles R. Jonassaint, Jude C. Jonassaint & Laura M. De Castro

Pages: 389-404
Published online: 28 Jul 2011

Article

Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice ›

James Elander, Mary Catherine Beach & Carlton Haywood Jr

Pages: 405-421
Published online: 28 Jul 2011

Article

Race and social attitudes about sickle cell disease ›

Shawn M. Bediako & Kimberly R. Moffitt

Pages: 423-429
Published online: 28 Jul 2011

Article

Barriers to conceiving sibling donors for sickle cell disease: perspectives from patients and parents ›

Gina A. Jae, Adam K. Lewkowitz, Joanna C. Yang, Liang Shen, Amal Rahman & Gustavo Del Toro

Pages: 431-445

Ethnicity & Health

Ruha Benjamin

Pages: 447-463

Published online: 28 Jul 2011

829 Views | 29 CrossRef citations | 1 Altmetric

Article

‘I can die today, I can die tomorrow’: lay perceptions of sickle cell disease in Kumasi, Ghana at a point of transition

Jemima A. Dennis-Antwi, Lorraine Culley, David R. Hiles & Simon M. Dyson

Pages: 465-481

Published online: 28 Jul 2011

3041 Views | 30 CrossRef citations | 2 Altmetric

Article

Feasibility of preconception screening for thalassaemia in Indonesia: exploring the opinion of Javanese mothers

Costrie Ganes Widayanti, Annastasia Ediati, Moedrik Tamam, Sultana M.H. Faradz, Erik A. Sistermans & Anne Marie C. Plass

Pages: 483-499

Published online: 28 Jul 2011

279 Views | 7 CrossRef citations | 0 Altmetric

Explore articles

Latest | Open access | Most read | Most cited | Trending

Explore the most recently published articles

Disparities in osteoarthritis diagnosis and symptoms between English- and Spanish-speaking Latinas over 40 years of age in the United States: a analysis of the Behavioral Risk Factor Surveillance System

Avery Dutcher et al.

Article | Published online: 9 Apr 2023

Ethnicity & Health

Deepika Rao et al.

Article | Published online: 2 Apr 2023

Depression impairment among young adult college students: exploring the racial paradox ›

Hans Oh et al.

Brief Report | Published online: 30 Mar 2023

View all latest articles ›

Ethnicity & Health
Vol. 16, Nos. 4–5, August–October 2011, 343–359

Routledge
Taylor & Francis Group

'All her children are born that way': gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya

Vicki M. Marsh[a,b,c]*, Dorcas M. Kamuya[a] and Sassy S. Molyneux[a,b,c]

[a]*Kenya Medical Research Institute (KEMRI) Wellcome Trust Research Programme, Social and Behavioural Group, PO Box 230, Kilifi 80108, Kenya;* [b]*Centre for Clinical Vaccinology and Tropical Medicine (CCVTM), Nuffield Department of Medicine, Oxford University, Old Road Campus, Headington, Oxford OX3 7LF, UK;* [c]*Ethox Centre, Department of Public Health and Primary Health Care (DPHPHC), Oxford University, Old Road Campus, Headington, Oxford OX3 7LF, UK*

(*Received 10 June 2010; final version received 17 November 2010*)

Objectives. To explore early experiences of sickle cell disorder (SCD) in families with a young affected child, and the way these experiences influence relations within families. To consider ways in which stigma could be counteracted in health and research programmes in sub Saharan Africa.

Design. A qualitative study was conducted in a rural area of coastal Kenya including in-depth interviews with 13 families affected by SCD and 12 staff of a local biomedical research progamme. Purposive selection aimed to maximize diversity in socioeconomic and educational status, religion, severity of illness burden and religion amongst families and draw on relevant experience for staffs. Interviews were recorded, transcribed and analysed using the constant comparative method for family interviews and a thematic framework approach for staff data.

Results. Low initial recognition of SCD and its cause were associated with lay practices of surveillance within affected families, contributing to stigmatisation that occurred independently of genetic knowledge. Blame was often placed on mothers, including a risk of blame for misaligned paternity. Mothers are often particularly affected by SCD through the loss of independent livelihoods and their limited options in coping with this chronic condition.

Conclusions. Mothers of children with SCD were particularly vulnerable to stigmatisation within families, with underlying structural influences that suggest these findings may apply to other similar settings in Africa, and have relevance for other genetic conditions. The potential, nature and form of stigmatisation point to the role of effective communication and SCD management in addressing for blame and discriminative effects of having a child with SCD. The findings highlight the importance of broader social programmes targeting underlying gender and economic inequalities.

Keywords: sickle cell disorder; Africa; stigmatisation; gender; health policy

Background

Internationally, many social and ethical issues have been debated around genetic testing, both for the 'new' post-genomic era of genetics (Collins 1999, Hoedemaekers *et al.* 2006, Parker *et al.* 2009) that began with the initiation of the Human Genome

*Corresponding author. Email: vmarsh@kilifi.kemri-wellcome.org

ISSN 1355-7858 print/ISSN 1465-3419 online

DOI: 10.1080/13557858.2010.541903
http://www.informaworld.com

Ethnicity & Health
Vol. 16, Nos. 4–5, August–October 2011, 465–481

Routledge
Taylor & Francis Group

'I can die today, I can die tomorrow': lay perceptions of sickle cell disease in Kumasi, Ghana at a point of transition

Jemima A. Dennis-Antwi[a], Lorraine Culley[b], David R. Hiles[b] and Simon M. Dyson[c]*

[a]*Investing in Midwives Programme, International Confederation of Midwives, 85 Freetown Avenue, La Bawaleshie, East Legon, P.M.B. L19, Accra, Ghana;* [b]*Applied Social Sciences, De Montfort University, Hawthorn Building, Leicester LE1 9BH, UK;* [c]*Unit for the Social Study of Thalassaemia and Sickle Cell, De Montfort University, Hawthorn Building, Leicester LE1 9BH, UK*

(*Received 17 June 2010; final version received 8 October 2010*)

Objective. To describe the lay meanings of sickle cell disease (SCD) in the Ashanti region of Ghana.
Design. Depth interviews with 31 fathers of people with SCD; a focus group with health professionals associated with the newborn sickle cell screening programme, and a focus group with mothers of children with SCD.
Results. Whilst there are discourses that associate sickle cell with early or recurrent death, with supernatural undermining of family well-being, and with economic challenges in purchasing medical care, other discourses that value children and other family practices that resist stigma are also in evidence.
Conclusion. Lay perspectives on SCD are constructed in the contexts of enduring culture (the high value placed on children); changing culture (medicine and research as available alternative discourses to supernatural ones); altered material circumstances (newborn screening producing cohorts of children with SCD); changing political situations (insurance-based treatment); enhanced family resources (the experience of a cohort of young people with SCD). Above all the praxis of successfully caring for a child with SCD, and the political experience of sharing that praxis, stands in opposition to discourses of death and helps parents resist stigma and despair.

Keywords: sickle cell disease; chronic illness; genetics; lay perspectives; culture; newborn screening; stigma; Ghana

Introduction

In this paper we consider sickle cell disease (SCD) in Ghana as an instance in understanding lay perspectives on chronic illness. Although there is a long history of considering lay perspectives, much of this focuses on North America and Europe. Moreover, any focus on lay perspectives in the developing world runs the risk of emphasising exotic notions of difference, constructing so-called 'primitive' lay views in opposition to 'advanced' medical knowledge of SCD. We begin with an overview of sickle cell in Ghana, a major chronic illness in West Africa, and the potential of newborn screening as a public health intervention. We then situate the issue of lay

*Corresponding author. Email: sdyson@dmu.ac.uk

ISSN 1355-7858 print/ISSN 1465-3419 online

DOI: 10.1080/13557858.2010.531249
http://www.informaworld.com

Ethnicity & Health
Vol. 16, Nos. 4–5, August–October 2011, 483–499

Feasibility of preconception screening for thalassaemia in Indonesia: exploring the opinion of Javanese mothers

Costrie Ganes Widayanti[a,b], Annastasia Ediati[b,c], Moedrik Tamam[d], Sultana M.H. Faradz[c], Erik A. Sistermans[e] and Anne Marie C. Plass[c,f]*

[a]*Biomedical Postgraduate Program on Genetic Counseling, Faculty of Medicine, Diponegoro University, Semarang, Indonesia;* [b]*Faculty of Psychology, Diponegoro University, Semarang, Indonesia;* [c]*Centre for Biomedical Research (CEBIOR), Faculty of Medicine, Diponegoro University, Semarang, Indonesia;* [d]*Department of Paediatrics, Faculty of Medicine, Diponegoro University/Dr. Kariadi Hospital, Semarang, Indonesia;* [e]*Department of Clinical Genetics, VU University Medical Center, Amsterdam, The Netherlands;* [f]*EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands*

(*Received 31 May 2010; final version received 15 February 2011*)

Background. Thalassaemia has become a major public health issue in Indonesia. It has been estimated that up to 10% of the population carries a gene associated with beta-thalassaemia. Currently, there is no formal recommendation for thalassaemia screening. This study aimed to explore awareness of thalassaemia, and to explore attitudes regarding carrier testing among Javanese mothers.

Methods. A quantitative questionnaire, designed using constructs of the Theory of Planned Behaviour, was applied cross-sectionally.

Results. Out of 191 mothers who were invited, 180 agreed to participate (RR = 94%), of whom 74 had a child affected with thalassaemia. Both attitudes towards receiving information about thalassaemia, and attitudes towards carrier testing were very positive. Awareness of thalassaemia was poor. Mothers, both those with and without an affected child, had barely heard of thalassaemia, nor of carrier testing. However, all mothers, including those with an affected child expressed high levels of interest in carrier testing. Respondents did not perceive that they had any control over carrier testing, and feared stigmatization and being discriminated against if their carrier status was identified. Attitudes towards carrier testing explained 23% of future reproductive intentions, in addition to perceived stigmatization, education level and 'mother's age' ($R^2 = 0.44$; $p = 0.001$).

Conclusion. Responding mothers expressed high levels of interest in receiving information on both thalassaemia and carrier testing. The less educated and the more deprived they were, the keener they were to receive this information. Overall, awareness of thalassaemia was low. Even mothers with affected children seemed unaware of the inheritance pattern and the recurrent risk of having an affected child in a subsequent pregnancy, showing the need for genetic counselling in Indonesia. It is therefore recommended not only to raise awareness about thalassaemia, but to improve the education of healthcare professionals as well.

Keywords: thalassaemia; carrier screening; Javanese mothers; genetic awareness; Theory of Planned Behaviour (TpB); awareness; Indonesia

*Corresponding author. Email: anne.marie.plass@kpnmail.nl

ISSN 1355-7858 print/ISSN 1465-3419 online

DOI: 10.1080/13557858.2011.564607
http://www.informaworld.com