



PSYCHOLOGICAL DISTRESS AMONG INFORMAL CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A SYSTEMATIC REVIEW

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ABSTRACT

Taking care of children with autism spectrum disorder (ASD) is extremely demanding, both physically and mentally, and can have a negative impact on the family. It takes a lot of time, effort, and patience to meet the extra care needs of the affected children. This often causes parents and other informal caregivers to experience psychological distress, depression, and other mental health issues. The databases reviewed for this literature review included CINAHL, PubMed Google Scholar and other Open Access gray literature. The literature searches took place between September 2023 and January 2024. A total of 2,605 studies were identified. Of these, 91 Randomized Control Trial studies met the inclusion criteria, and 14 had sufficient data to conduct a systematic review including subgroup analysis. The result of the reviews showed that informal caregivers of people with a autistic spectrum disorder are at increased risk of developing depression, anxiety, and stress, so preventive interventions are need.

Key words: Autism Spectrum Disorder (ASD), Caregiving, Informal caregivers, Family impact, Psychological distress, Mental health, Depression, Anxiety

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INTRODUCTION

It has been observed in available literature that Autism Spectrum Disorder (ASD) which is one of the most common forms of neurodevelopmental disorder in children defined by difficulties in social interaction and communication as well as displays of repetitive behavior (Keyes, et al, 2012; Elamin & Al-Ayadhi, 2014). According to Baxter et al., (2015), 1% of global population is affected by autism spectrum disorder and in the last few decades the prevalence rate has increased dramatically from 1 in 166 children to 1 in 68, making it a global health crisis (Patricia, 2012). Although till date, the exact cause of autism is not known but it is widely believed that a combination of genetic and environmental factors plays a role (Gadad et al., 2013).

In 2017, according to World Health Organization factsheet entitled “autism spectrum disorders”, autism imposes significant economic and emotional burdens not only on the patients but also on their families and caregivers (WHO, 2017). Till date, there is no known treatment available to cure autism, and therefore, extra care is needed for the child with ASD, which in most cases is challenging for the caregiver due to the presence of extensive physical and developmental comorbidities,

such as motor deficits, seizure, and delayed self-help skills (Lord et al., 2012; Picardi et al., 2018). It has been observed that caring for a child with autism has been associated with family stress, and increase in physical and psychological problems, especially for informal caregivers compared with other types of disabilities. Informal caregivers (parents, relatives, friends etc) of children with autism have to deal with the various forms of severe disabilities present in the child and bear the psychological, social, financial and social burden of the child's condition. It has been reported that they are prone to social isolation, ‘burn out syndrome’ and they are more likely to suffer from mental disorders such as depression and anxiety (Mojeed et al., 2013).

Informal caregivers or parents of children with autism shoulder a disproportionate amount of responsibility that comes with caring for children with ASD, such as addressing a child's social, physical, emotional, and educational requirements, which can lead to distress, despair, and anxiety (DePape & Lindsay, 2015). It has been reported in previous studies that caring for children with ASD poses a higher risk of experiencing mental health

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conditions than bringing up children with other disorders or normally developing children (Falk et al., 2014; Hu et al., 2019). The mental health and psychological problems among parents and informal caregivers of ASD include depression, stress, anxiety, and emotional disturbance, which may, in fact, lead to suicidal tendencies (Al-Farsi et al., 2016; Montes & Cianca, 2014; Patra & Kumar Patro, 2019). Besides, many parents of children with autism experiences financial difficulties as a result of expensive out-of-pocket medical expenditures, underemployment or job loss (Cidav et al., 2012). According to study by Mohammadi and Zarafshan (2014), mothers of children with autism reported poor overall mental health, and those whose children showed higher levels of behavioral problems experienced greater stress.

Available literature has shown that few studies have reported the effect of having a child with autism on informal caregivers' physical and mental health. In Oman, a study reported that fathers are 1.8 times more likely to develop depression, anxiety and stress than fathers of normal children (Al-Farsi, et al., 2016). Also, in Qatar, a study investigating informal caregivers' concerns about their children found caregivers pessimism about their children's future and had high anxiety about the

services provided to their children (Kheir et al., 2012). In Europe, America and Arab/Muslim people, several studies conducted has revealed that parents of children with autism suffer from psychological disorders including stress, anxiety and depression more than parents of children with normally developing children. This is because raising a child with autism usually imposes a significant burden on parents and caregivers, the Arab Gulf countries and Pakistan found that anxiety, stress, and depression are more common among mothers of children with autism and intellectual disability compared to control groups (Bilali et al., 2018). Another study conducted in 2015 revealed that mothers of ASD children have a higher rate of stress and have an increased rate of use of antidepressant and psychoactive medications than fathers of ASD children (Bilali et al., 2018). Psychological distress is a general construct that indicates the stress and demands of daily life have surpassed an individual's coping mechanisms (Veit & Ware, 1983). It reflects a range of symptoms and states, often closely aligned with anxiety and depression, from mild levels of mental distress to severe psychiatric conditions (McLachlan & Gale, 2018).

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Despite the above stated problems of psychological distress on informal caregivers of children with autism, to the best of my knowledge no systematic review has examined the literature on psychological distress as it relates to help-seeking behaviour and health literacy. The purpose of the current review was to collate, synthesize, and evaluate the

METHOD

Search Strategy

This systematic review used the abridged guidelines for preferred reporting items for systematic reviews and meta-analyses (Moher et al., 2015). A systematic search of the literature was conducted using the PRISMA strategy (Moher et al., 2015). The databases reviewed for this literature review included CINAHL, PubMed, and Google Scholar. The literature searches took place between September 2023 and January 2024. The search terms and Boolean operators were used with the following keywords: *psychological distress, health literacy, help-seeking behaviour, informal caregiver, autism, and stress*. This systematic literature search was applied to abstracts, keywords, and titles of the articles. Furthermore, hand searches were conducted on the reference sections of the full text review articles and any meta-analyses/systematic reviews found in the

available research on psychological distress among informal caregivers of children with autism. Moreover, this review aimed to synthesize what is known about psychological distress among informal caregivers of children with autism and the role of help-seeking behaviour and health literacy.

search. In order to improve quality, grey literature was excluded as these have not undergone peer review and are therefore not bound by high standards of quality, which could limit the ability to draw firm conclusions (Adams et al., 2017).

Selection/Eligibility Criteria

Studies were included in this study if they met the following criteria:

1. published within a peer-reviewed journal between 2010 to date;
2. not a systematic review or meta-analysis;
3. available in English;
4. reported quantitative data on psychological distress of informal caregivers of children with autism; and,
5. explicitly use the phrase psychological distress in title, abstract, review of literature or discussion of results. The review did not restrict any study based

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on the study design or age of participants.

Studies were excluded if they: (1) if they were conference papers and other none peer review publications; (2) psychological distress of other participants, (e.g. general public); and, (3) if they were published before 2010. No restrictions were placed on the age of participants.

Data Extraction

Information extraction included: citation; study design; sample size and characteristics; measurements of psychological distress and relevant analyses and results.

Quality Assessment

The methodological quality of included studies was assessed by the researcher

Results

Help-seeking behaviour: Informal caregivers believed in the value and importance of seeking help and using services in seven studies (Honey et al., 2015; Hurley et al., 2017; 2018; Mohammad et al., 2012; Montgomery & Terrion, 2016). Informal caregivers in four studies reported that they had taken or were willing to take whatever steps necessary to help and support their child through a mental health problem. A cross-sectional

using the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2009). The MMAT is a reliable method of assessing study quality relative to the methodology and design employed with substantial inter-rater reliability (Pace et al., 2012). Quantitative studies are sub-divided into randomised controlled trials, non-randomised trials and descriptive studies. Articles are assessed against four dimensions of quality based on design and are allocated one point per criteria met. Studies are determined to be of low methodological quality if 0-25% of criteria are met, of moderate methodological quality if 50%-75% of criteria are met and of high quality if 100% of criteria are met.

study found that foster carers' favourable attitudes to help-seeking were associated with both contacting and referral to mental health services but not actual service use (Bonfield et al., 2010). Previous exposure and experience of mental illness and service use was associated with a willingness to seek help in two studies (Honey et al., 2015; Hurley et al., 2017). In contrast, parents in two other studies held negative attitudes (e.g. fear, mistrust, lack of faith) to mental

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health services that was based on observation of others' unsuccessful help-seeking experience (Jeong et al., 2017; Umpierre et al., 2015).

Health Literacy: Literature search with keywords health literacy and caregivers yielded 105 results. After filtering the search to include studies of informal caregivers and those that were peer-reviewed, the results yielded a total of 44 articles. Upon further review, only eight articles were pertinent to the study. An additional search was completed separately

using keywords above and merged together for the literature review. After reviewing the abstracts, only articles that focused on health literacy, informal caregivers or autism were selected. No studies were found that specifically evaluated the role of health literacy and help-seeking behaviour on psychological distress. The review of the literature yielded several themes related to the study: health literacy, mental health literacy, informal caregivers', stress, psychological distress, autism, quality of life, and burden.

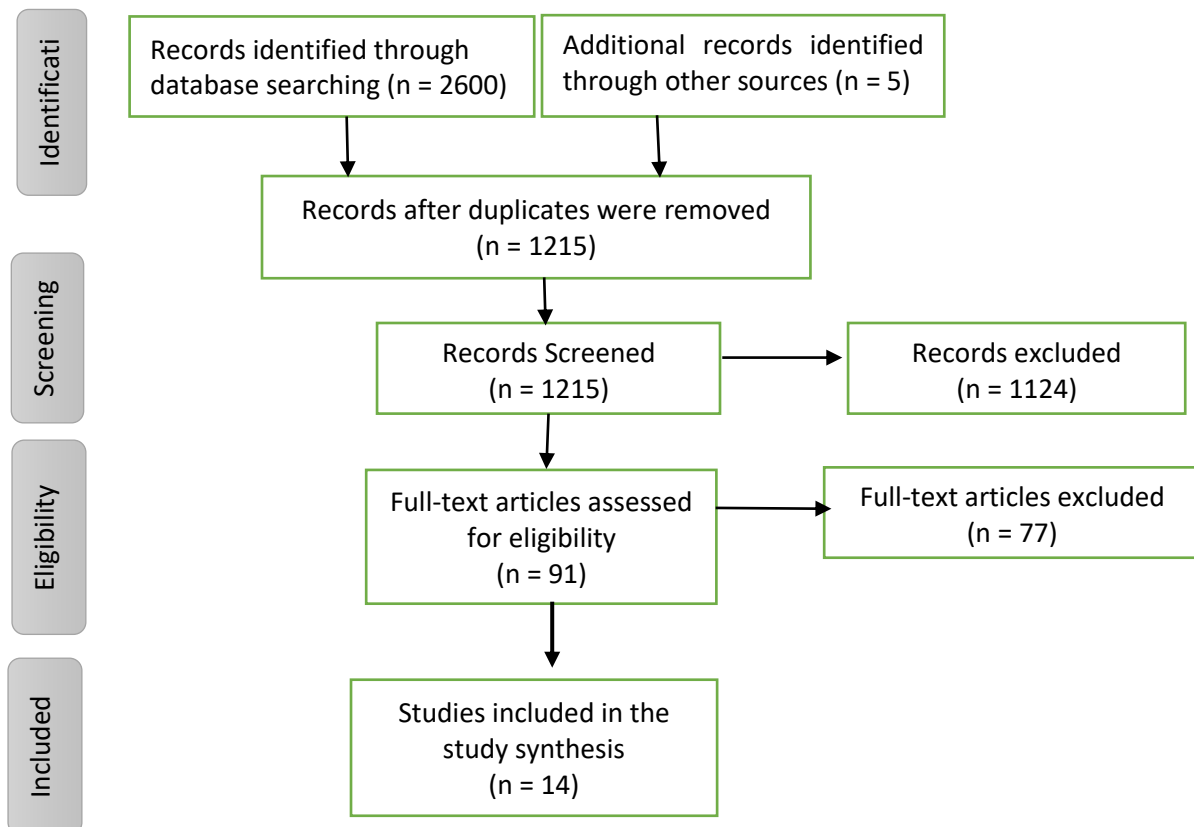


Fig 1: PRISMA (Moher et al., 2015) flow diagram

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Most of the relevant studies included in this literature review have shown parents raising a child with ASD are at increased risk of a mental health disorder, particularly anxiety and depression, when compared to the general population (Schnabel, Youssef, et al., 2020). This risk is multifactorial. Genetic liability, developmental characteristics of the child, caregiving stress, social stigma, and procuring as well as paying for the child's healthcare all place substantial demands on parents (Falk et al., 2014; Hsiao, 2016).

In Oman, a study reported that fathers are 1.8 times more likely to develop depression, anxiety and stress than fathers of normal children (Al-Farsi et al., 2016). In Qatar, a study examining caregivers' concerns about their children found caregivers pessimism about their children's future and had high anxiety about the services provided to their children (Kheir et al., 2012). Several studies conducted in Europe, America and Arab/Muslim people revealed that parents of children with autism suffer from psychological disorders including stress, anxiety, and depression more than parents of children with normally developing children (Benrween et al., 2022). This is because raising a child with

autism usually imposes a significant burden on parents and caregivers, the Arab Gulf countries and Pakistan found that anxiety, stress, and depression are more common among mothers of children with autism and intellectual disability compared to control groups (Bilali et al., 2018). Another study conducted in 2015 revealed that mothers of ASD children have a higher rate of stress and have an increased rate of use of antidepressant and psychoactive medications than fathers of ASD children (Bilali et al., 2018). A study in the US during the COVID-19 pandemic by Kalb et al., (2021) examined the mental health of parents raising a child with ASD during the early stages of the COVID-19 pandemic. Results demonstrated substantially higher levels of psychological distress, particularly those related to feelings of panic, among parents raising a child with ASD when compared to parents in the US as a whole.

Ethnic, cultural and religious affiliation were related to parents' perceptions of appropriate help-seeking strategies (Honey et al., 2015; Jeong et al., 2017; Mohammad et al., 2012). For caregivers in Malaysia, mental health services were limited, and caregivers tried alternative treatments, based on religious or spiritual beliefs

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(Mohammad et al., 2012). Korean-American fathers had the final say in seeking help for their child as they were the primary income earners and thus the decision maker in Korean culture (Jeong et al., 2017).

The nature of the mental health problem was also an important factor in whether or not parents would take action and seek help. For example, qualitative studies indicated that parents and caregivers were likely to take action if they observed children's disruptive externalising behaviour or changes in personality (Honey et al., 2015; Hurley et al., 2017; Jeong et al., 2017; York

& Jones, 2017). In a cross-sectional study, the presence of a mental health problem in a child (scoring in the abnormal or borderline range) was associated with a greater likelihood of problem detection, referral to mental health services, and service use (Bonfield et al., 2010). In another study with Australian parents, the greater impact of a mental health disorder on youth daily functioning was associated with a greater perceived need for parental help, with 100% of parents of youths with a severe mental health disorder perceiving need for help compared to 68.3% of parents of youths with a mild mental health disorder (Lawrence et al., 2015).

DECLARATIONS:

1. **Declaration of Originality:** We declare that this manuscript is my original work and has not been submitted or published elsewhere. We have reviewed and approved the final version of the manuscript.
2. **Conflict of Interest:** We declare that there are no conflicts of interest regarding the publication of this paper.
3. **Informed Consent:** Informed consent was obtained from all individual participants included in the study.

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REFERENCES

- Adams, R. J., Smart, P., & Huff, A. S. (2017). Shades of grey: Guidelines for working with the grey literature in systematic reviews for management and organizational studies. *International Journal of Management Reviews*, 19(4), 432–454.
- Autism spectrum disorders [Internet]. World Health Organization. World Health Organization; [8 Dec 2017]. Available from: <http://www.who.int/mediacentre/factsheets/fs108/en/>
- Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbati, M. M., & Al-Adawi, S. (2016). Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case-control study. *Neuropsychiatr Dis Treat.*, 12, 1943-51.
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G., (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological medicine*, 45(3), 601-13.
- Benrween, A., Alazabi, T., Abukash, H., Alnajjar, N., Ejdeah, N., Shileebik, M., Alharari, M., Tellib, M., & Alborai M. (2022). Psychological Distress among Libyan Mothers of Autistic Male Children in Tripoli, Libya. *Alq J Med App Sci.* 5(1), 267-273.
- Bilali, R., Alqahtani, A., Asiri, A., Hakami, F., Otain, M., Asseri, H., & Al-Zaalh, M., (2018). Depression, Anxiety and stress among mothers of autism spectrum disorder children. *Int J Med Res Prof.*, 4(1), 453-58.
- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129(4), 617-23.
- DePape, A. M., & Lindsay, S. (2015). Parents' Experiences of Caring for a Child With Autism Spectrum Disorder, 25(4), 569-83.
- Elamin, N. E., & Al-Ayadhi, L. Y. (2014). Brain autoantibodies in autism spectrum disorder. *Biomarkers in medicine*, 8(3), 345-52.
- Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *J Autism Dev Disord.*, 44(12), 3185-203.
- Gadad, B. S., Hewitson, L., Young, K. A., & German, D. C. (2013). Neuropathology and animal models of autism: genetic and environmental factors. *Autism research and treatment*, 73, 19 - 35.
- Honey, A., Alchin, S., & Hancock, N. (2014). Promoting mental health and wellbeing for a young person with a mental illness: parent occupations. *Australian Occupational Therapy Journal*, 61, 194-203.
- Honey, A., Chesterman, S., Hancock, N., Llewellyn, G., Hazell, P., & Clarke, S. (2015). Knowing what to do and

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- being able to do it: Influences on parent choice and use of practices to support young people living with mental illness. *Community Mental Health Journal*, 51, 841-851.
- Hsiao, Y.-J. (2016). Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbor support. *Research in Autism Spectrum Disorders*, 23, 122–130.
- Hu, X., Han, Z. R., Bai L, & Gao, M. M. (2019). The Mediating Role of Parenting Stress in the Relations Between Parental Emotion Regulation and Parenting Behaviors in Chinese Families of Children with Autism Spectrum Disorders: A Dyadic Analysis. *J Autism Dev Disord.*, 49(10), 3983-98
- Hurley, D., Swann, C., Allen, M. S., Okely, A. D., & Vella, S. A. (2017). The role of community sports clubs in adolescent mental health: the perspectives of adolescent males' parents. *Qualitative Research in Sport, Exercise and Health*, 9, 372-388.
- Hurley, D., Allen, M. S., Swann, C., Okely, A. D., & Vella, S. A. (2018). The development, pilot, and process evaluation of a parent mental health literacy intervention through community sports clubs. *Journal of Child and Family Studies*, 1-12.
- Jeong, Y. M., McCreary, L. L., & Hughes, T. L. (2017). Qualitative study of depression literacy among Korean American parents of adolescents. *Journal of Psychosocial Nursing and Mental Health Services*, 56, 48-56.
- Kalb, L. G., Badillo-Goicoechea, E., Hologue, C., Riehm, K. E., Thrul, J., Stuart, E. A., Smail, E. J., Law, K., White-Lehman, C., & Fallin, D. (2021). Psychological distress among caregivers raising a child with autism spectrum disorder during the COVID-19 pandemic. *Autism Research*, 14(10), 2183–2188.
- Kheir, N. M., Ghoneim, O. M., Sandridge, A. L., Hayder, S. A., Al-Ismail, M. S., Al-Rawi, F. (2012). Concerns and considerations among caregivers of a child with autism in Qatar. *BMC Resources Notes*, 6, 5 - 12.
- Lawrence, D., Johnson, S., Hafekost, J., Boterhoven De Haan, K., Sawyer, M., Ainley, J., & Zubrick, S. R. (2015). *The Mental Health of Children and Adolescents. Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing.* Canberra: Department of Health
- Lord C, Petkova E, Hus V, Gan W, Lu F, Martin DM, et al. (2012). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Arch Gen Psychiatry*, 69(3), 306-13
- Mohamad, M. S., Zabidah, P., Fauziah, I., & Sarnon, N. (2012). Mental health literacy among family caregivers of schizophrenia patients. *Asian Social Science*, 8, 74-82.
- Mohammadi, M., & Zarafshan, H. (2014). Family function, parenting style and broader autism phenotype as predicting factors of psychological adjustment in typically developing siblings of children with autism spectrum disorders. *Iranian journal of psychiatry*, 9(2), 55-63.

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- Moher, D., Shamseer, L., Clarke, M., Gherzi, D., Liberati, A., Petticrew, M., ... & Stewart, L. A. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4, 1-8.
- Mojeed, M., Omigbodun, O., Ogun, O., Adewuya, A., & Adedokun, B., (2013). The relationship between the pattern of impairments in autism spectrum disorder and maternal psychosocial burden of care. *OA Autism*, 1(1), 4.
- Montgomery, N. D., & Lennox Terrion, J. (2016). Tensions along the path toward mental health literacy for new immigrant mothers: perspectives on mental health and Patricia, B. K., & Endowed, E. D. L. (2012). Autism Worldwide: Prevalence, Perceptions, Acceptance, Action. *Journal of Social Sciences*, 8(2).
- Patra, S., & Kumar Patro, B. (2019). Affiliate stigma among parents of children with autism in eastern India. *Asian journal of psychiatry*, 44, 45-7.
- Pluye, P., Gagnon, M. P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *International Journal of Nursing Studies*, 46, 529-546.
- Umpierre, M., Meyers, L. V., Ortiz, A., Paulino, A., Rodriguez, A. R., Miranda, A., ... & McKay, M. M. (2015). Understanding Latino parents' child mental health mental illness. *International Journal of Mental Health Promotion*, 18, 83-94.
- Montes, G., & Cianca, M. (2014). Family Burden of Raising a Child with ASD. In: Patel VB, Preedy VR, Martin CR, editors. *Comprehensive Guide to Autism*. New York, NY: Springer New York; 2014. p. 167-84.
- Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies*, 49, 47-53.
- Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M, et al. (2018) Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison Groups. *Clinical practice and epidemiology in mental health*, 14, 143-76.
- literacy: Todos a bordo/all aboard. *Research on Social Work Practice*, 25(5), 607-618.
- Veit, C. T., & Ware, J. E. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology*, 51(5), 730-742.
- York, W., & Jones, J. (2017). Addressing the mental health needs of looked after children in foster care: the experiences of foster carers.



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*Journal of Psychiatric and Mental
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