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***This undergraduate research project – “Social Supports for Adolescent and Young Adult Polycystic Ovary Syndrome Patients: A Scoping Review” by Caitlin E. Mungall – was one of the recipients of a Western Libraries Undergraduate Research Award for the 2022–2023 competition. On their applications, students were required to submit answers to four research reflection questions together with their research project.**

What is your research project about and why is it important?

Polycystic ovary syndrome (PCOS) is a chronic disorder with negative health consequences for millions of women. The paucity of research regarding interventions targeting the psychosocial symptoms of PCOS for adolescents and young adults (AYAs), susceptible to low self-esteem and depression, warranted this review. This paper provides an overview of research on the social supports currently available for AYAs and identifies areas where further research is required to elucidate their support needs. A scoping review methodology identified 15 studies that met inclusion criteria. Findings revealed that this is an emerging field of research and most included studies originated in North America. Thematic organization of the findings suggested two broad themes: pre-diagnostic support concerns and post-diagnostic support resources. Within the first theme, three sub-themes arose: (dis)satisfaction with information received about PCOS, delayed diagnoses, and a need for increasing healthcare provider support. A lack of research specific to the support needs of transgender PCOS patients was additionally identified. The results of this study can be used to inform the development of evidence-based support interventions and educational requirements for graduate school curriculums that enable future healthcare providers to adequately provide support when diagnosing, educating, presenting treatment options, and directing PCOS patients to support resources.

How did you choose your research topic and/or design your research question?

The intersection of women and health is a broad area of research that I am thoroughly interested in, inspired partly by the lack of research specific to women’s health concerns that have reflected those who were conducting scientific research in the past – primarily white men. This lack of research specific to women’s needs understandably yields negative health outcomes. Over the past six months, I have experienced firsthand the stress and loneliness of navigating a PCOS diagnosis, and from this position, I narrowed down my area of interest to a more specific research question that suited the requirements of my Academic Health Communication course; what social supports are available for adolescent and young adult PCOS patients? Initially, I had considered a topic reviewing the self-esteem issues of PCOS undergraduate students, however after preliminary searching and a discussion with my professor, I determined there was not enough critical mass of literature in this emerging field for such a specific question, leading me to adjust my question and determine my final topic. This



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experience was a unique opportunity to become intimately acquainted with the body of literature regarding my condition and contribute meaningfully by synthesizing this information.

How did you find library/archives services and resources for your research topic?

In week five of our course, a Western teaching and learning librarian conducted a tutorial focusing on systematic and scoping reviews and effective database searching. Vital information about eligibility criteria, information sources, and crafting a search with keywords, MeSH headings, and Boolean operators was covered. Additionally, the librarian directed us to further pre-recorded library presentations, “How to Conduct a Search for a Scoping Review” and “Covidence 101”, to inform our assignments. With this information and after consultation with another research librarian, I developed a search strategy on MEDLINE (Ovid) that I recreated in three other databases: EMBASE (Ovid), PsycINFO (Ovid), and CINAHL. The steps in my process included:

- Developing my research question: “What social supports are available for adolescent and young adult PCOS patients?”
- Isolating the key concepts from my research question: social support, PCOS, adolescents and young adults
- Brainstorming keywords (a comprehensive list can be found in the Appendix of my paper)
 - Social support: Self-Help Groups (MeSH), social care, online social support
 - PCOS: polycystic ovarian syndrome, Stein Leventhal syndrome
 - Adolescents and young adults: teenagers, youth
- Combining search results using OR then AND Boolean operators
- The final search provided 21 articles on MEDLINE (Ovid)

What library/archives services and resources did you use to perform your research?

The beginning of my considerable usage of library services and resources involved attending a Systematic/Scoping Review online workshop on January 31st, followed by an in-class presentation by a librarian regarding systematic and scoping reviews and effective database searching on February 7th. I also booked an online systematic/scoping review consultation with a research librarian regarding my preliminary search strategy on March 7th. I watched Videos and How-Tos on the Western Libraries website to supplement this information, including “Review Articles: A very brief introduction” and “Get it @ Western not working.” Access to articles through Western databases proved to be immensely valuable, and when I could not access full-text articles, a librarian at Allyn and Betty Taylor Library helped me with the process of requesting full-text articles through Interlibrary Loans. I requested four digitized articles using this service during my article screening process in Covidence. I used the Ask: Chat with a Librarian service extensively for advice, such as how some of the study designs of my included



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articles could be classified. Additionally, I completed the majority of the writing for my paper in the John and Dotsa Bitove Family Law Library – a quiet study space where I could be productive.

Social Supports for Adolescent and Young Adult Polycystic Ovary Syndrome Patients:

A Scoping Review

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Social Supports for Adolescent and Young Adult Polycystic Ovary Syndrome Patients: A Scoping Review

Polycystic ovary syndrome (PCOS) is a complex endocrine, metabolic, and reproductive condition characterized by numerous negative consequences for the long-term health and fertility of millions of women globally (Riesterberg et al., 2021). The widely-used 2003 Rotterdam diagnostic criteria for PCOS specifies that two of three criteria must be satisfied for a diagnosis of PCOS to be determined: biochemical or clinical hyperandrogenism, irregular menstrual cycles, and polycystic ovarian morphology on ultrasound (Escobar-Morreale, 2018). In adolescents, the two former criteria must be observed (Escobar-Morreale, 2018). Long-term health and pregnancy-related morbidities associated with PCOS include a higher risk of gestational diabetes, gestational hypertension, preeclampsia, myocardial infarction, Type 2 Diabetes Mellitus, and stroke (Riesterberg et al., 2021). In addition, high levels of psychosocial distress accompany a diagnosis of PCOS; it is a chronic condition for which there is no cure and limited medical treatment options are available for symptoms such as absent, irregular, heavy or painful periods, subfertility, obesity, acne, alopecia, and hirsutism (excess hair growth) (Percy et al., 2009).

Abundant research literature concerning the experience of adolescents and young adults (AYA) aged 10 to 25 with cancer accessing social support groups provides a foundation from which to approach support services for patients of the same age range who have PCOS, another chronic condition (Zebrack & Isaacson, 2012). In a review of evidence-based psychosocial support interventions for AYAs with cancer and other life-threatening or chronic diseases, Zebrack & Isaacson (2012) found that peer support programs facilitate the establishment of

social ties between young people with cancer, allowing the sharing of coping skills and information, and emotional support through the sharing of fears and concerns.

According to the findings of a qualitative study conducted by Ismayilova & Yaya (2022a) exploring what can be done to improve PCOS healthcare, women emphasized the need for improvement of support services such as increased information and awareness of the condition among primary care physicians, resources such as funding for further PCOS research, and the availability of age-specific support groups and mental health supports. A review of PCOS support groups and their role in awareness, advocacy, and peer support highlights that they are an essential setting through which women can receive information about their condition, maintain healthy lifestyle habits, share knowledge and experience, and acquire emotional and social support (Avery et al., 2020). A study of the emotional needs of teenagers with PCOS by Dowdy (2012) suggests that nurses are ideally suited to developing and encouraging local and community support groups for this population. The study posits that the emotional and social support needs of teenagers with PCOS must be adequately assessed before methods of assisting them with coping with the physical symptoms of the chronic condition are employed (Dowdy, 2012).

Other forms of PCOS social support interventions, such as Roessler et al.'s (2012) group counselling and aerobic exercise program, emphasize how individual relationships between participants can similarly cause changes in behaviour and a reduction of social isolation. A qualitative assessment of online PCOS support group discussion forums by Holbrey & Coulson (2013) suggests that digital avenues for social support also hold the potential to facilitate empowering experiences such as connecting with others who understand the condition, accessing

information and advice, improving adjustment to and management of PCOS, and the opportunity to interact with healthcare professionals.

Unfortunately, despite a prevalence of 5-20% of women of reproductive age, there remains a paucity of research regarding interventions targeting the psychosocial symptoms of PCOS (Percy et al., 2009). The adolescent and young adult years are tumultuous times in an individual's development. During these years, low self-esteem prospectively predicts depression, partly through an increased tendency to ruminate about perceived negative aspects of the self (Orth et al., 2008). Thus, with limited options for the medical treatment of symptoms, AYAs diagnosed with PCOS must have access to support and information, for example in the form of social support interventions. The objective of the present study is to provide an overview of the extent, nature, and range of research pertaining to the social support needs of adolescent and young adult PCOS patients, and the social supports currently available to this population (Arksey & O'Malley, 2005). Additionally, areas where further research in the literature base is required to identify the unique social support needs of youth with PCOS will be identified.

Methods

For inclusion in this scoping review, studies must have explicitly focused on social support and involved adolescent or young adult PCOS patients (an age range of 10 to 25 years old). Studies were excluded if an age group inclusive of adolescents or young adults was not specified, and therefore did not address the research objective. Given that the author speaks English, studies were included if they were written or translated into English. No limits were applied for the study design, geographical location, or publication dates for the search so that this scoping review could capture all relevant published studies. Grey literature was not searched due to time constraints, a limitation that will be discussed later in this paper.

To identify potentially relevant documents, four databases were searched on March 18th, 2023: MEDLINE (Ovid), EMBASE (Ovid), PsycINFO (Ovid), and CINAHL. The search strategy was crafted after consultation with an experienced research librarian at Western University. For MEDLINE, MeSH headings included Self-Help Groups, Social Support, Polycystic Ovary Syndrome, Adolescent, and Young Adult. Some of the 69 additional keywords used in combination with OR and AND Boolean operators are as follows: support group, social care, polycystic ovarian syndrome, stein leventhal syndrome, and youth. The detailed search strategy for MEDLINE can be found in the Appendix. Search results from each database were exported as RIS files and imported to the web-based software Covidence for title and abstract screening and full-text screening.

The scoping review methodology proposed by Arksey & O'Malley (2005) informed this scoping review, a framework that includes five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results. After study selection in Covidence, a data charting form was developed on the database programme Excel based on characteristics identified by Arksey & O'Malley (2005): author(s), year of publication, study location, study population, study design, aims of the study, and important results that relate to the research objective. The year of publication is relevant in determining whether this field of research is emerging or well-established, and the study location is relevant in determining the geographic distribution of studies in this area of research. The study design was charted (e.g., qualitative, mixed methods) as a means of 'mapping' the research area (Arksey & O'Malley, 2005).

Following stage five of the Arksey & O'Malley (2005) framework, charts were constructed mapping the distribution of studies chronologically, geographically, and according to

study design, illuminating the dominant research areas. Secondly, thematic organization of the reported research findings was undertaken to identify the social support needs of AYA PCOS patients, the range of social supports currently available, and to locate gaps in the literature.

Findings

A total of 56 studies were imported into Covidence for screening, from MEDLINE (n = 21), EMBASE (n = 25), PsycINFO (n = 1), and CINAHL (n = 9). As indicated by the PRISMA Flow Diagram presented in Figure 1, 16 duplicate records were removed, 19 records were determined to be irrelevant to the present research objective through title and abstract screening, and after the full-text screening of the remaining 21 articles, 5 articles were excluded because they did not explicitly focus on social support, and 1 article was excluded because it did not specify the age of the sample population, and therefore an age range inclusive of AYAs could not be determined. Consequently, a total of 15 studies were included in this scoping review. For all studies, the data charted included the author(s), year of publication, study location, study population, study design, aims, and key findings related to the research objective. Table 1 provides a visual representation of this summary of the evidence, except for the key findings related to the research objective that will be discussed below.

Literature on the social support needs of AYA PCOS patients, and the social supports that are currently available to them is recent and has increased considerably over the past few years, as shown in Figure 2. The first study was published in 2005, indicating that this is an emerging field of research. Among the included studies, 47% (n = 7) were published in the last five years of this current study (2018-2022), and 87% (n = 13) were published in the past ten years (2012-2022).

Regarding the geographic scope of the included literature, North America was the world region in which the majority of the included studies originated, responsible for 53% of the reported findings. Within North America, the United States was the country of origin for 40% ($n = 6$) of the reported findings, and Canada was responsible for 13% ($n = 2$). The United Kingdom was the country of origin for 20% ($n = 3$) of the included studies. However, it is notable that two studies (Gibson-Helm et al., 2016; Holbrey & Coulson, 2013) recruited participants online, so the demographic data of research participants are not restricted to those in the United Kingdom. Australia, China, Denmark, and New Zealand each individually contributed to 7% ($n = 1$) of the included studies. Refer to Figure 3 for a visual representation of the geographic distribution of included studies.

As indicated in Figure 4, a qualitative research design was employed for the majority of the studies included in this review ($n = 6$). Mixed-methods designs were also featured frequently for $n = 4$ studies. Of the remaining studies, $n = 1$ was cross-sectional, $n = 2$ were systematic reviews, and $n = 2$ were evidence-based practice articles. Among the qualitative studies, $n = 3$ collected data via semi-structured interviews, $n = 2$ collected data through the administration of an online questionnaire, and $n = 1$ used both semi-structured interviews and satisfaction surveys. Studies of a mixed methods design utilized a broad range of data collection, such as weight, waist circumference, aerobic capacity measurements, Physical Activity Enjoyment Scale (PACES) assessment, a Modified Polycystic Ovary Syndrome Health-related Quality of Life Questionnaire (MPCOSQ), semi-structured interviews, and online questionnaires.

Pre-Diagnostic Support Concerns

During the thematic organization of the research findings, two broad themes relevant to the research objective emerged: pre-diagnostic support concerns and post-diagnostic support

resources. Within the first theme, three sub-themes arose: (dis)satisfaction with information received about PCOS, delayed diagnoses, and a need for increasing healthcare provider support.

(Dis)satisfaction with Information Received About PCOS

Reported extensively across $n = 5$ studies was a sense of dissatisfaction with the information PCOS patients received about their condition, while $n = 3$ studies delineated the empowering aspects of being able to access information. A systematic review specific to PCOS support groups revealed that few women were satisfied with the information received about their condition, thereby creating opportunities to improve women's access to evidence-based information (Avery et al., 2020). Gibson-Helm et al. (2016) note that among their online questionnaire participants, few were satisfied with the information they received (15.6%) and satisfaction with the information they received about PCOS was positively associated with diagnosis satisfaction. In a qualitative study employing online questionnaires, Hoyos et al. (2020) found that 57.3% of patients were dissatisfied with overall care. In Ismayilova & Yaya's (2022b) study examining patient satisfaction and experiences with PCOS, 66% of patients reported dissatisfaction with the information provided about PCOS at the time of their diagnosis, and many reported not having received any information regarding lifestyle management (42%) or medical therapy options (28%). A subsequent study by Ismayilova & Yaya (2022a) regarding what could be done to improve PCOS healthcare identified the need for credible doctor-provided information, potentially in the form of pamphlets and websites.

In a qualitative investigation of peer-to-peer online support, Holbrey & Coulson (2013) identify accessing information and advice as an empowering process. A qualitative study conducted by Weiss and Bulmer (2011) revealed how participants pursue useable information and support through the Internet, seeking solace online by reading about other women with

PCOS. Snyder (2005) posits that through education, adolescents can become knowledgeable about PCOS and available treatment options, thereby empowering them to make informed healthcare decisions and highlighting the need for individuals to receive adequate information.

Delayed Diagnoses

Frustration with delayed diagnoses was often cited in studies (n = 4), a logical extension of dissatisfaction with the information patients received about their PCOS. Gibson-Helm et al. (2016) reported that more than one-third of questionnaire participants had waited longer than two years and seen three or more health professionals before a diagnosis was provided, and 35.2% reported dissatisfaction with their diagnosis experience. Some women have attributed delays in diagnoses to a failure on the part of the healthcare providers to recognize the condition; others mention delaying seeking a diagnosis when their symptoms first arose, sometimes because of feelings of embarrassment (Hadjiconstantinou et al., 2017). Another group of women experienced primary care physicians disregarding their concerns, refusing to provide referrals, and seldom ordering further tests to investigate concerns (Ismayilova & Yaya, 2022b). Participants in Weiss & Bulmer's (2011) semi-structured interviews described witnessing gaps in their physician's knowledge that resulted in a delayed diagnosis, insensitive care, and poor conveyance of information.

Increasing Healthcare Provider Support

The inadequate information PCOS patients report receiving from their healthcare providers about their condition and delayed diagnoses highlight a need for increasing the support provided by healthcare workers. An analysis by Hoyos et al. (2020) revealed that obstetrician-gynecologist residencies in the United States average a minimal 4% of total block time on reproductive endocrinology and infertility, and of these residencies, 5.5% do not offer any such

rotations. Similarly, Ismayilova & Yaya's (2022a) qualitative study suggests a need for established PCOS organizations to help train and retrain doctors due to a need for greater knowledge and awareness of PCOS in primary care physicians. A systematic review of health-related quality of life in AYAs with PCOS suggests that they did not appreciate discussions within their patient-provider relationship about their condition directed toward their parents rather than themselves (Kaczmarek et al., 2016). Conversely, Weiss & Bulmer (2011) described participants who regarded their physician's care as competent, even though it could be a source of frustration. Frustration tended to center on the physician's focus on fertility and disregard for other PCOS-related issues and the inclination to prescribe oral contraceptives as a form of treatment without exploring other options or even describing what PCOS means – effectively cutting the patient out of the decision-making process (Weiss & Bulmer, 2011).

Dowdy postulates that the diverse range of needs of teenagers with PCOS, including management challenges, medical treatment, learning needs, and emotional and social issues, warrants a holistic approach to the care of PCOS in this population that can allow nurses and practitioners to enhance their quality of life (2012). Positive and supportive relationships between healthcare providers and adolescents diagnosed with PCOS can permit them to express concerns and feelings about their chronic condition, which can have a significant impact on body image and self-esteem (Snyder, 2005). Hadjiconstantinou et al. (2017) propose a need to educate healthcare providers and the broader community to increase support.

Post-Diagnostic Support Resources

The second theme identified in the literature encompasses the variety of support resources currently available to adolescents and young adults with PCOS: support groups, online

peer support, group education, multidisciplinary care, a mobile phone-based psychological adjustment communication system, and exercise fitness programs.

Support groups are currently the most prevalent of the available supports, cited in $n = 3$ studies included in this review. One of these studies is a systematic review of support groups for PCOS, synthesizing the results from five studies, providing further evidence of this form of support as the most common, allowing women to seek information, emotional, and social support, and the opportunity to share knowledge and experiences (Avery et al., 2020).

Participants in Ismayilova & Yaya's (2022a) study noted a need for increased age-specific support groups and mental health supports to be available. Positive aspects of support groups described by Snyder (2005) include an ability to build relationships with other adolescent PCOS patients and the subsequent provision of psychosocial support.

Akin to face-to-face support groups, online peer support has shown promise, with $n = 2$ included studies specific to virtual forms of support. Empowering processes such as connection, information, interaction with healthcare professionals, and improved adjustment and management have been reported in peer-to-peer online support forums and groups, although feeling like an 'outsider' and reading about the negative experiences of others were described as disempowering processes (Holbrey & Coulson, 2013). Interestingly, in Hoyos et al.'s (2020) study, among patients with PCOS, an impressive 98.2% had searched for information about PCOS online, but only 18.8% joined an online support group or forum.

Group education sessions are discussed in $n = 2$ studies. Avery et al. (2020) emphasize a need for support and presentations at patient forums and workshops. In a study conducted by Hadjiconstantinou et al. in 2017, participants were in favour of group education for women with PCOS.

Kaczmarek et al. (2016) believe in a multidisciplinary approach to supporting distressed adolescent PCOS patients, including care by a general internist or pediatrician, and potential referral to a dietitian, endocrinologist, or mental health professional. In further support of multidisciplinary management, a qualitative review of an integrated, evidence-based PCOS service established that women were satisfied with its appropriateness and effectiveness, reporting positive health impact and improved emotional well-being (Tay et al., 2021). This integrated care encompasses education, lifestyle coaching, consideration of the individual's preferences, and multidisciplinary management of PCOS features (Tay et al., 2021).

Although the results of this study are not yet published, Tan et al. (2022) have registered a study protocol for the development and evaluation of a psychological adjustment communication system for adolescents with PCOS at a high risk of depression, another avenue for social support that will be pursued soon.

Two different fitness program intervention studies relevant to social support for PCOS patients were identified in the literature. A dance-based support group (Go Girls!) for girls at risk for PCOS by King et al. (2019) aimed to encourage physical activity and simultaneously improve the enjoyment of exercise in adolescent girls because weight loss can reduce the hyperandrogenemia associated with PCOS. Consequently, 40% of the participants showed decreased free testosterone levels, and the girls enjoyed the exercise and made further lifestyle changes outside of the program (King et al., 2019). An alternate exercise-based approach proposed by Roessler et al. (2012) involved group counselling for eight weeks followed by a high-intensity aerobic exercise program (running or indoor cycling) for eight weeks or vice versa. The authors found that supportive relationships were expressed as group cohesion, and the

intervention yielded beneficial effects on well-being, health, and exercise behaviour (Roessler et al., 2012).

Research Gap

Throughout the process of data charting and summarizing the results for this review, a paucity of research on the support needs specific to transgender PCOS patients were identified; every study included focused solely on female patients, and one systematic review had transgender PCOS patients listed as exclusion criteria (Kaczmarek et al., 2016). Compared to cisgender youth, an emerging body of literature suggests that transgender youth experience higher rates of depression, suicidality, and self-harm (Connolly et al., 2016). Therefore, the unique support needs of this population should be studied so relevant support interventions can be implemented – perhaps ones that use gender-affirming language and provide an opportunity to connect with other transgender PCOS patients.

Discussion

In this scoping review, 15 studies were identified addressing the social support needs and support resources available to adolescent and young adult PCOS patients. Findings indicate that AYA PCOS patients frequently express dissatisfaction with the information they have received about their condition, delayed diagnoses, and subsequently, a need to increase the provision of support by healthcare providers so that patients can become better informed about their health and receive diagnoses in a more timely manner. Post-diagnosis support resources available to AYA PCOS patients vary widely and include support groups, online peer support, group education, multidisciplinary care, a mobile phone-based psychological adjustment communication system, and exercise fitness programs.

Policymakers can leverage these findings to allocate funding and broadly implement evidence-based support interventions, for example, dance programs for youth with or at risk for PCOS. Additionally, regarding medical and nursing school curriculums and residencies, policies should be written to ensure future healthcare providers are adequately educated about the varying presentations and symptoms of PCOS and the needs of PCOS patients so that they can more effectively provide support when diagnosing, educating the patient, presenting treatment options, and directing them to support resources, such as local or virtual support groups. Keeping the findings of this review in mind, patients can advocate for the level of care they deserve from their healthcare providers and use an awareness of the available support options to make an informed decision about which best suits their unique needs.

This scoping review has some limitations. Although an AYA population was present in the participant age range for each study, each study had a different combination of ages represented outside of this age range. Therefore, some results and qualitative participant testimonies may have been from PCOS patients outside this age range. Due to time constraints, to make this review more feasible, grey literature was not searched in conjunction with the database searches, so relevant articles may have been missed. Additionally, as indicated in Figure 3, of the 15 included studies, 14 were conducted in high-income countries, except for one that originated in China (“High Income Countries 2023,” 2023; Tan et al., 2022). Future research should therefore be conducted in low and middle-income countries to ascertain whether any differences in support needs and resources are present. Based on the literature gap identified in this review, future research should additionally aim to be more inclusive of a transgender youth PCOS patient population.

References

- Avery, J., Ottey, S., Morman, R., Cree-Green, M., & Gibson-Helm, M. (2020). Polycystic ovary syndrome support groups and their role in awareness, advocacy and peer support: A systematic search and narrative review. *Current Opinion in Endocrine and Metabolic Research*, *12*, 98–104. <https://doi.org/10.1016/j.coemr.2020.04.008>
- Connolly, M. D., Zervos, M. J., Barone, C. J., Johnson, C. C., & Joseph, C. L. M. (2016). The Mental Health of transgender youth: Advances in understanding. *Journal of Adolescent Health*, *59*(5), 489–495. <https://doi.org/10.1016/j.jadohealth.2016.06.012>
- Dowdy, D. (2012). Emotional needs of teens with polycystic ovary syndrome. *Journal of Pediatric Nursing*, *27*(1), 55–64. <https://doi.org/10.1016/j.pedn.2010.08.001>
- Escobar-Morreale, H. F. (2018). Polycystic ovary syndrome: Definition, aetiology, diagnosis and treatment. *Nature Reviews Endocrinology*, *14*(5), 270–284. <https://doi.org/10.1038/nrendo.2018.24>
- Gibson-Helm, M., Teede, H., Dunaif, A., & Dokras, A. (2016). Delayed diagnosis and a lack of information associated with dissatisfaction in women with polycystic ovary syndrome. *The Journal of Clinical Endocrinology & Metabolism*. <https://doi.org/10.1210/jc.2016-2963>
- Hadjiconstantinou, M., Mani, H., Patel, N., Levy, M., Davies, M., Khunti, K., & Stone, M. (2017). Understanding and supporting women with polycystic ovary syndrome: A qualitative study in an ethnically diverse UK sample. *Endocrine Connections*, *6*(5), 323–330. <https://doi.org/10.1530/ec-17-0053>
- High-Income Countries 2023. (2023). In *World Population Review*. Retrieved April 5, 2023, from <https://worldpopulationreview.com/country-rankings/high-income-countries>

- Holbrey, S., & Coulson, N. S. (2013). A qualitative investigation of the impact of peer to peer online support for women living with polycystic ovary syndrome. *BMC Women's Health, 13*(1). <https://doi.org/10.1186/1472-6874-13-51>
- Hoyos, L. R., Putra, M., Armstrong, A. A., Cheng, C. Y., Riestenberg, C. K., Schooler, T. A., & Dumesic, D. A. (2020). Measures of patient dissatisfaction with health care in polycystic ovary syndrome: Retrospective analysis. *Journal of Medical Internet Research, 22*(4). <https://doi.org/10.2196/16541>
- Ismayilova, M., & Yaya, S. (2022a). What can be done to improve polycystic ovary syndrome (PCOS) healthcare? insights from semi-structured interviews with women in Canada. *BMC Women's Health, 22*(1). <https://doi.org/10.1186/s12905-022-01734-w>
- Ismayilova, M., & Yaya, S. (2022b). “I felt like she didn’t take me seriously”: A multi-methods study examining patient satisfaction and experiences with polycystic ovary syndrome (PCOS) in Canada. *BMC Women's Health, 22*(1). <https://doi.org/10.1186/s12905-022-01630-3>
- Kaczmarek, C., Haller, D. M., & Yaron, M. (2016). Health-related quality of life in adolescents and young adults with polycystic ovary syndrome: A systematic review. *Journal of Pediatric and Adolescent Gynecology, 29*(6), 551–557. <https://doi.org/10.1016/j.jpag.2016.05.006>
- King, McGill-Meeks, Beller, & Burt Solorzano. (2019). Go Girls!—dance-based fitness to increase enjoyment of exercise in girls at risk for PCOS. *Children, 6*(9), 99. <https://doi.org/10.3390/children6090099>

- Orth, U., Robins, R. W., & Roberts, B. W. (2008). Low self-esteem prospectively predicts depression in adolescence and young adulthood. *Journal of Personality and Social Psychology, 95*(3), 695–708. <https://doi.org/10.1037/0022-3514.95.3.695>
- Percy, C. A., Gibbs, T., Potter, L., & Boardman, S. (2009). Nurse-led Peer Support Group: Experiences of women with polycystic ovary syndrome. *Journal of Advanced Nursing, 65*(10), 2046–2055. <https://doi.org/10.1111/j.1365-2648.2009.05061.x>
- Riestenberg, C., Jagasia, A., Markovic, D., Buyalos, R. P., & Azziz, R. (2021). Health care-related economic burden of polycystic ovary syndrome in the United States: Pregnancy-related and long-term health consequences. *The Journal of Clinical Endocrinology & Metabolism, 107*(2), 575–585. <https://doi.org/10.1210/clinem/dgab613>
- Roessler, K. K., Glintborg, D., Ravn, P., Birkebaek, C., & Andersen, M. (2013). Supportive relationships – psychological effects of group counselling in women with polycystic ovary syndrome (PCOS). *Communication and Medicine, 9*(2), 125–131. <https://doi.org/10.1558/cam.v9i2.125>
- Snyder, B. (2005). Polycystic ovary syndrome (PCOS) in the adolescent patient: recommendations for practice. *Pediatric nursing, 31*(5), 416-421.
- Tan, H., Gao, L., Guo, Y., Liu, Y., Ding, R., Yan, X., Wang, X., Wang, Y., & Wang, L. (2022). Development and evaluation of a psychological adjustment communication system for adolescents with polycystic ovary syndrome at a high risk of depression: A mixed-method study protocol. *Frontiers in Psychiatry, 13*. <https://doi.org/10.3389/fpsy.2022.937280>
- Tay, C. T., Pirota, S., Teede, H. J., Moran, L. J., Robinson, T., Skouteris, H., Joham, A. E., & Lim, S. S. (2021). Polycystic ovary syndrome models of care: A review and qualitative

evaluation of a guideline-recommended integrated care. *Seminars in Reproductive Medicine*, 39(03/04), 133–142. <https://doi.org/10.1055/s-0041-1727191>

Weiss, T. R., & Bulmer, S. M. (2011). Young women's experiences living with polycystic ovary syndrome. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 40(6), 709–718. <https://doi.org/10.1111/j.1552-6909.2011.01299.x>

Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, 30(11), 1221–1226. <https://doi.org/10.1200/jco.2011.39.5467>

Table 1*Summary of Evidence for Included Studies*

Author(s)	Year of publication	Study location	Study population	Study Design	Aim
Avery et al.	2020	New Zealand	Women with PCOS	Systematic review	Review and summarise current literature relating to PCOS support groups
Dowdy	2012	United States	Teens with PCOS	Evidence-based practice	Identify emotional aspects of teens with PCOS in healthcare settings
Gibson-Helm et al.	2016	United Kingdom	18 to 35 years	Cross-sectional	Investigate PCOS diagnosis experiences, information provided, and concerns about PCOS.
Hadjiconstantinou et al.	2017	United Kingdom	17 to 51 years	Qualitative	Explore women's experiences living with PCOS, and the potential acceptability of group education sessions
Holbrey & Coulson	2013	United Kingdom	20 to 45 years	Qualitative	Consider the experiences of women living with PCOS who access and participate in an online support group discussion forum

Author(s)	Year of publication	Study location	Study population	Study Design	Aim
Hoyos et al.	2020	United States	18 to 51+ years	Qualitative	Explore satisfaction with health care among patients with PCOS and their internet use
Ismayilova & Yaya	2022	Canada	18 to 63 years	Qualitative	Explore experiences of women with PCOS in navigating the healthcare system and their insights on what could be improved based on their lived experiences
Ismayilova & Yaya	2022	Canada	18 to 60 years	Mixed methods	Explore the perceptions and experiences of PCOS diagnosis in Canada
Kaczmarek et al.	2016	United States	13 to 24 years	Systematic review	Review recent data exploring the relationship between PCOS and health-related quality of life (HRQoL) in adolescents and its implication for management

Author(s)	Year of publication	Study location	Study population	Study Design	Aim
King et al.	2019	United States	7 to 21 years	Mixed Methods	Dance-based support group (Go Girls!) to entice physical activity and improve enjoyment of exercise
Roessler et al.	2012	Denmark	19 to 46 years	Mixed Methods, cross-over	Examine the psychological impact of a group-oriented approach to disease management and health behaviour in women with PCOS
Snyder	2005	United States	Adolescents with PCOS	Evidence-based practice	Provide recommendations for practice for nurses regarding adolescent PCOS patients
Tan et al.	2022	China	Adolescents with PCOS	Mixed Methods	Develop and evaluate the effectiveness of a psychological adjustment communication system (mobile phone-based) for reducing the prevalence of depression among adolescents with PCOS who are at a high risk of depression in China

Author(s)	Year of publication	Study location	Study population	Study Design	Aim
Tay et al.	2021	Australia	20 to 39 years	Review and qualitative evaluation	Review healthcare experiences of women with PCOS and available literature on PCOS-dedicated healthcare services, and qualitatively evaluate a guideline-translated PCOS MoC
Weiss & Bulmer	2011	United States	18 to 23 years	Qualitative	Explore the psychosocial effects of living with PCOS through the experiences of diagnosed young women

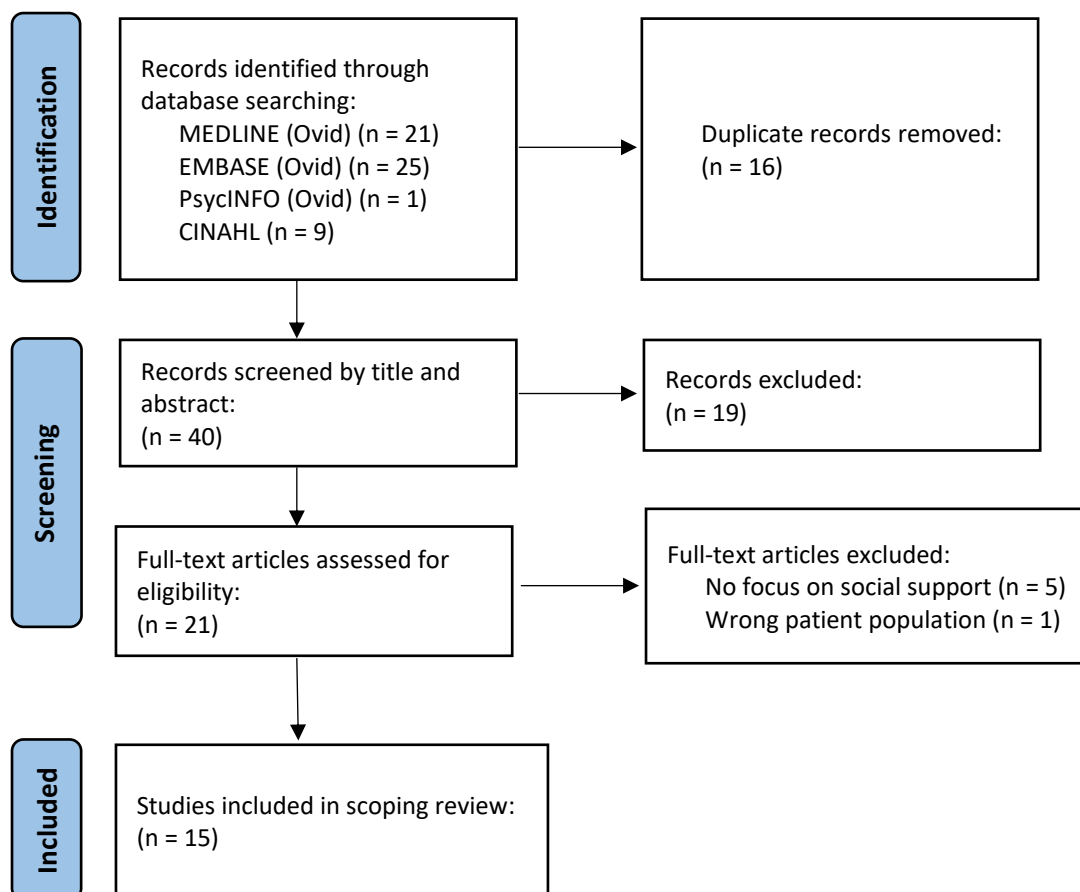
Figure 1*PRISMA Flowchart of study selection process*

Figure 2

Number of studies published per year

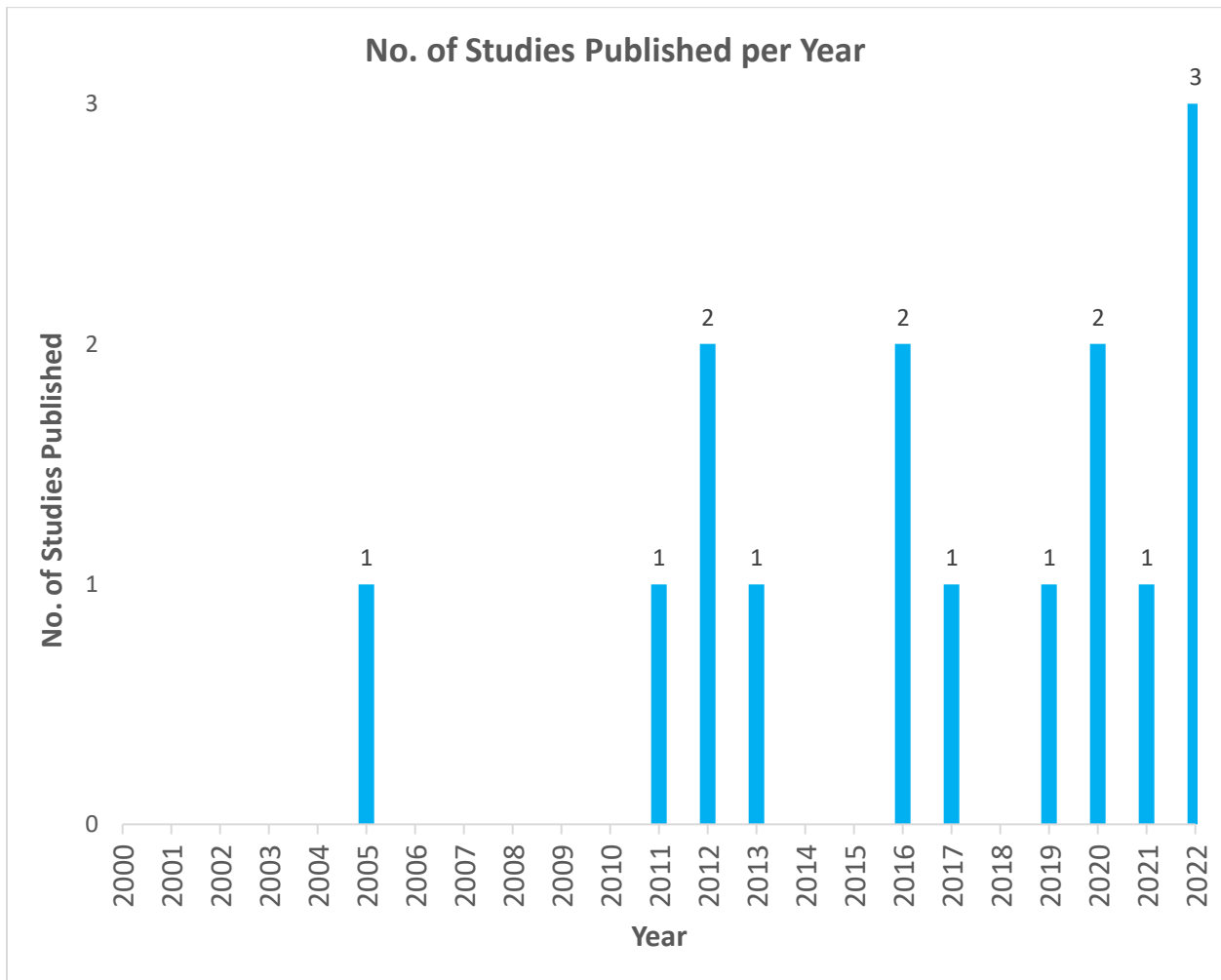


Figure 3

Geographic distribution of included studies

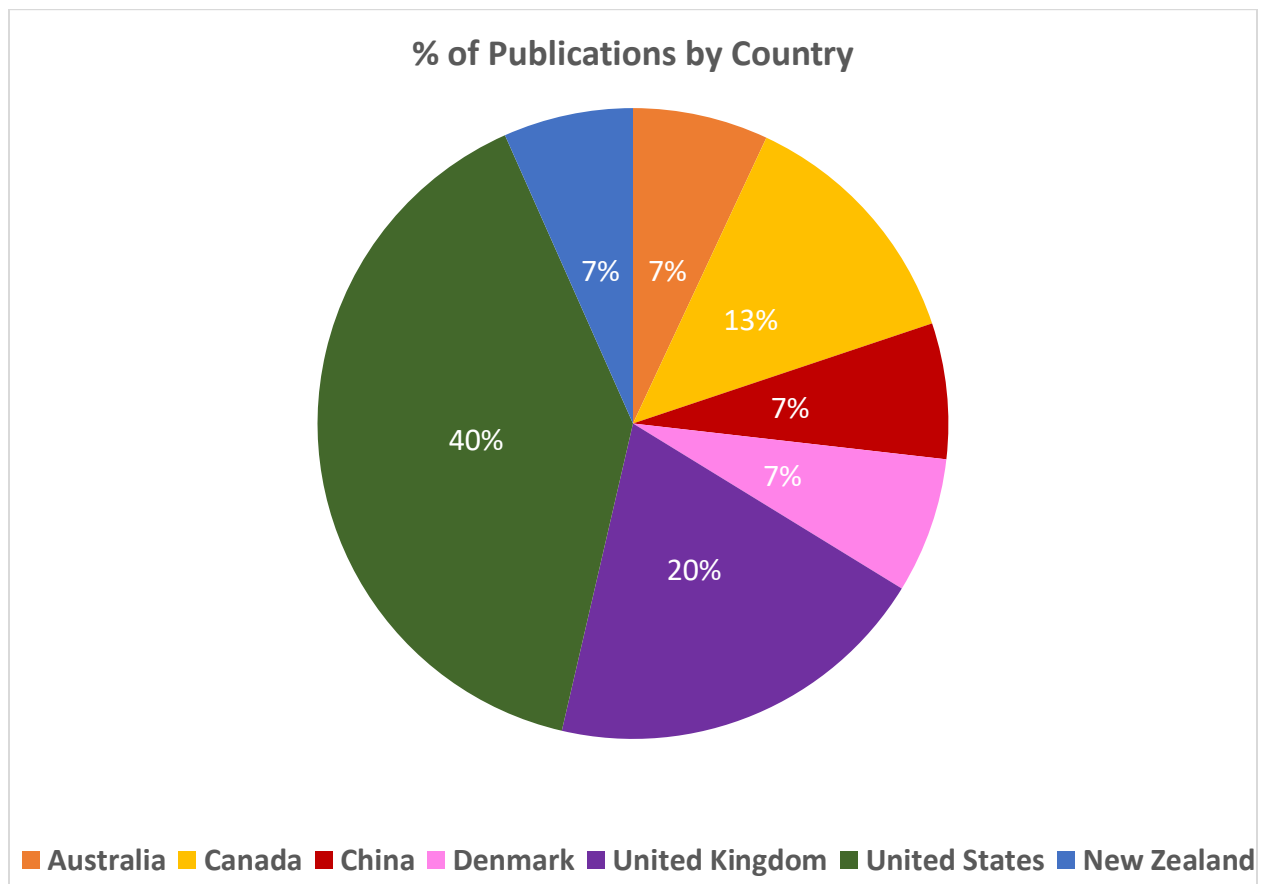
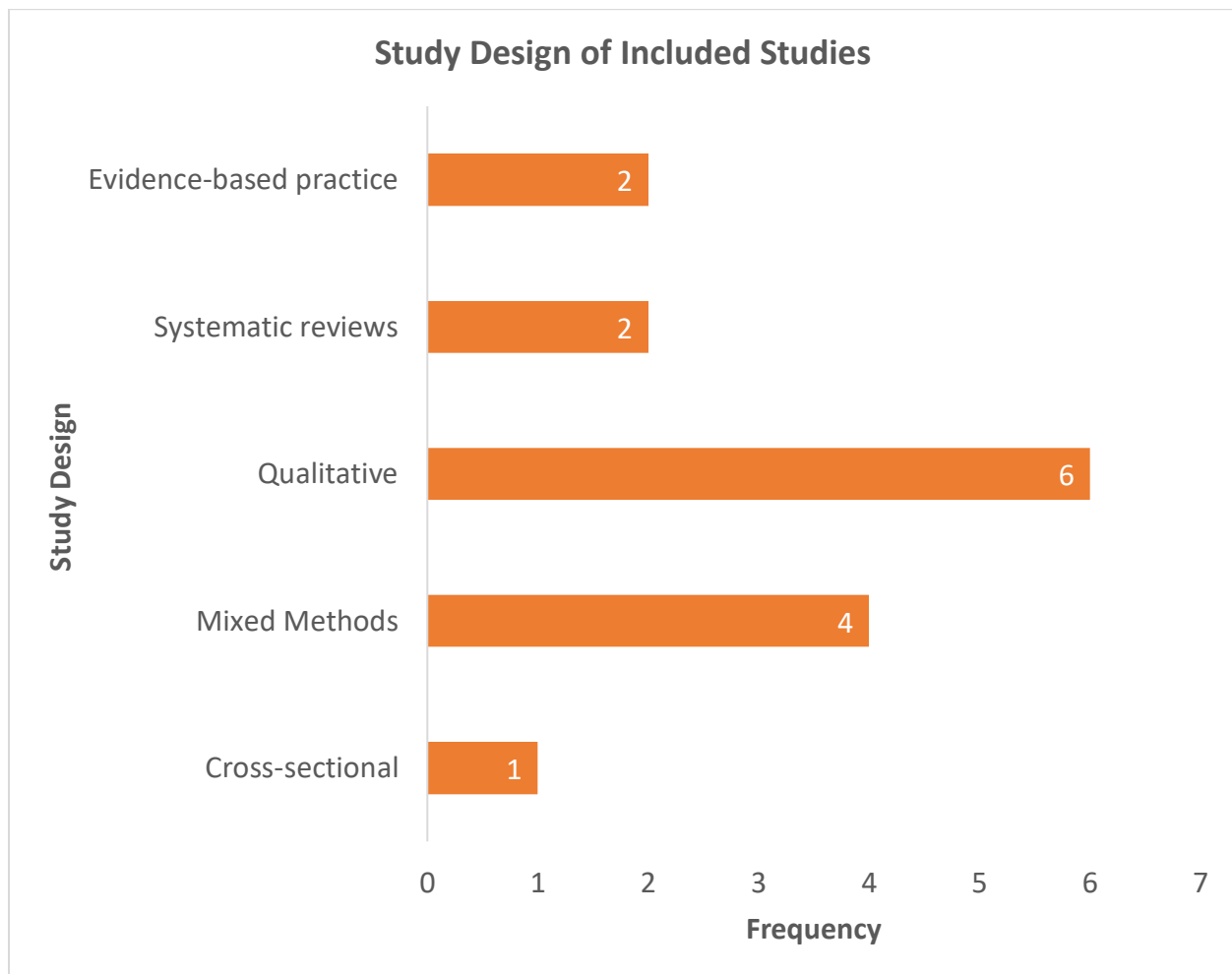


Figure 4

Study designs included in this scoping review



Appendix

Final Search Strategy for MEDLINE (Ovid) (Search Performed March 18, 2023)

#	Searches	Results
1	Self-Help Groups/ or Social Support/ or social support group.mp.	85860
2	club, therapeutic social.mp.	0
3	clubs, therapeutic social.mp.	0
4	group, self-help.mp.	18
5	group, support.mp.	795
6	groups, self-help.mp.	19
7	groups, support.mp.	237
8	self help groups.mp.	10259
9	self-help group.mp.	665
10	social club, therapeutic.mp.	0
11	social clubs, therapeutic.mp.	0
12	support group.mp.	4239
13	support groups.mp.	5658
14	therapeutic social club.mp.	7
15	therapeutic social clubs.mp.	2
16	care, social.mp.	945
17	online social support.mp.	183
18	online social supports.mp.	2
19	perceived social support.mp.	5250
20	perceived social supports.mp.	26
21	social care.mp.	8756
22	social support.mp.	105637
23	social support, online.mp.	24
24	social support, perceived.mp.	285
25	social supports, online.mp.	0
26	social supports, perceived.mp.	6
27	support, online social.mp.	4

28	support, perceived social.mp.	36
29	support, social.mp.	1260
30	supports, perceived social.mp.	0
31	polycystic ovary syndrome.mp. or Polycystic Ovary Syndrome/	21599
32	ovarian degeneration, sclerocystic.mp.	0
33	ovarian syndrome, polycystic.mp.	3
34	ovary, sclerocystic.mp.	0
35	ovary syndrome, polycystic.mp.	12
36	polycystic ovarian syndrome.mp.	3668
37	polycystic ovary syndrome.mp.	21599
38	polycystic ovary syndrome 1.mp.	6
39	sclerocystic ovarian degeneration.mp.	2
40	sclerocystic ovaries.mp.	37
41	sclerocystic ovary.mp.	43
42	sclerocystic ovary syndrome.mp.	35
43	stein leventhal syndrome.mp.	751
44	syndrome, polycystic ovary.mp.	41
45	syndrome, stein-leventhal.mp.	9
46	31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45	22834
47	group therapy.mp. or Psychotherapy, Group/	16382
48	community therapy.mp.	64
49	community treatment.mp.	2269
50	group psychotherapy.mp.	2889
51	group treatment.mp.	4610
52	psychotherapy, group.mp.	14599
53	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 47 or 48 or 49 or 50 or 51 or 52	149676
54	46 and 53	58
55	Adolescent/ or adolescent.mp.	2246698
56	young adult.mp. or Young Adult/	1031929
57	adolescence.mp.	93812
58	adolescent, female.mp.	1865

59	adolescents.mp.	236512
60	adolescents, female.mp.	1316
61	female adolescent.mp.	1388
62	female adolescents.mp.	4858
63	teen.mp.	6469
64	teenager.mp.	3229
65	teenagers.mp.	14054
66	teens.mp.	7484
67	youth.mp.	93282
68	youths.mp.	15060
69	adult, young.mp.	103
70	adults, young.mp.	382
71	young adult.mp.	1031929
72	young adults.mp.	84959
73	55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72	2825696
74	54 and 73	21