REMOTE GENETIC COUNSELING AND PSYCHOEDUCATION FOR PATIENTS WITH GENETIC ISSUES: A SYSTEMATIC LITERATURE REVIEW

Henri Setiawan[1*], Nur Hidayat[2], Doni Setiawan[3], Andan Firmansyah[4], Heri Ariyanto[5]

[1,2,4]Department of Nursing, STIKes Muhammadiyah Ciamis
[2]Department of Medical Laboratory Technology, STIKes Muhammadiyah Ciamis
[5]Master of Nursing Universitas Muhammadiyah Yogyakarta

Email Korespondensi: henrisetiawan1989@gmail.com

Disubmit: 29 Maret 2024 Diterima: 20 Juni 2024 Diterbitkan: 01 Juli 2024
Doi: https://doi.org/10.33024/mahesa.v4i7.14765

ABSTRACT

Remote technology refers to electronic information and telecommunication technologies utilized by medical personnel and doctors to manage patient health remotely. Such technologies encompass digital images, videos, or text files stored on computer systems. Technology-driven remote genetic counseling has demonstrated efficacy in enhancing the quality of life for patients afflicted with genetic disorders. Hence, researchers undertook a systematic review to assess the impact of remote technology interventions on the psychological well-being of patients with genetic diseases. Inclusion criteria comprised English articles published from 2012 to 2023 focusing on technology-based remote genetic counseling interventions for patients with genetic disorders, with outcomes pertaining to psychological well-being. Research designs included randomized controlled trials and quasi-experimental studies, while exclusion criteria encompassed literature reviews, systematic reviews, and scoping reviews. The review encompassed four databases: PubMed, Scopus, Proquest, and Wiley. Critical Appraisal Checklist from the Joanna Briggs Institute was employed for methodological assessment. The studies, comprising randomized controlled trials and quasi-experimental designs, met the inclusion criteria. The review of remote genetic counseling and psychoeducational interventions indicated a significant impact on psychological well-being, thereby enhancing the quality of life for patients with genetic disorders. remote genetic counseling and psychoeducational interventions interventions have been shown to ameliorate the psychological status of patients affected by genetic disorders, thereby enhancing their quality of life. Evidence-based interventions utilizing technology can be integrated into medical care systems to effectively manage patients with genetic disorders.

Keywords: Remote Genetic Counseling, Mobile Applications, Psychoeducation, Telephone, Web-Based

INTRODUCTION

Genetically based diseases are the primary causes of morbidity and death, which in turn affect societal health issues. Physical impairment and miscarriages are frequently caused by chromosomal

abnormalities. Humans are made up of fundamental genetic materials, or DNA, found in their chromosomes. DNA strands known as chromosomes are found in every living thing's cell. (Biesecker, 2020). 46 chromosomes, or 22 pairs of chromosomes, are present in each normal cell. Miscarriages, neonatal deaths, and Down syndrome newborns are frequently caused by chromosomal abnormalities. Humans are made up of fundamental genetic materials, or DNA, found in their chromosomes. DNA strands, or chromosomes, are found in every living thing's cell. 46 chromosomes make up a typical cell; they are comprised of one pair of sex (the X and Y chromosomes) that define gender and 22 pairs of body (autosomes, chromosomes 1 through 22). (Laksono et al,. 2011).

Stunted growth, delayed mental development, facial deformities, multiple body defects (e.g., heart valve leakage, cleft lip, and mental retardation), genital abnormalities, and a history of stillbirth or death in the first month of life are examples of manifestations of chromosomal abnormalities (Yahaya et al., 2021). In addition to chromosomal anomalies, dominant or recessive gene mutations in autosomes or sex chromosomes can result in genetic illnesses include dentigenesis imperfecta, achondroplasia, albinism, hemophilia, red-green color blindness, thalassemia, and penilketonura (Senaldi & Smith-Raska, 2020). Chromosomal abnormalities, on the other hand, might take the shape of mosaic chromosomes, abnormalities in chromosome structure, or abnormalities in the number of chromosomes, as in the cases of Down syndrome, Turner syndrome, and Klinefilter syndrome (Loveall et al., 2021).

There are differences in genetically transmitted illnesses' incidence and prevalence according to gender, geography, and ethnic group. 58 out of 1,000 infants had genetic illness, compared to 5–15% in Indonesia. With a frequency of 1 in 700 births, chromosomal abnormalities like Down syndrome (trisomy 21) are the most frequent diseases; they are more common in pregnant women over 35. With a frequency of 1 in 8,000 to 10,000 newborns born, trisomy13, also known as patau syndrome, is an extremely uncommon genetic disorder. Typically, the symptoms are so severe that they can result in death within a few hours or weeks of birth. Another uncommon condition is trisomy 18, or Edward's syndrome, which affects 1 in 1,500 newborns and causes mental impairment, development problems, tiny heads and hips, and deformities in the hands and feet (Sosiawan et al., 2021). The majority of illnesses are brought on by non-genetic environmental causes, while others are brought on by genetic-environment interactions. Certain disorders, such primary hypertension, asthma, schizophrenia, Parkinson's disease, and others, can be impacted by hereditary factors in addition to environmental variables. In Indonesia there is no definite and comprehensive data on the prevalence of genetic diseases and diseases that can be influenced by genetic factors, both narrow and broad in scope (Alshaya, 2022).

The prevalence of genetic diseases varies among different ethnicities, geographic regions, or genders. Worldwide, there are 6172 unique rare diseases, of which 71.9% are genetic in nature. The prevalence of genetic diseases is 58 per 1,000 births globally, whereas in Indonesia, 5-15% of the population

experiences genetic diseases (Nguengang Wakap et al., 2020). The pathogenesis in patients with genetic disorders is typically characterized by physical disabilities, cardiac abnormalities, mental disorders, and blood abnormalities. Consequently, these individuals often experience psychological issues such as anxiety and depression, ultimately affecting their quality of life. Quality of life is closely linked to health status, reflecting the individual's health impact on functional well-being and life perceptions. Given the significant impact of genetic disorders, researchers strive to explore new strategies for more effective and cost-efficient patient care, namely through psychoeducation and genetic counseling (El-Baky et al,. 2020)

Genetic counseling is a communication process aimed at addressing genetic diseases within families. The history of genetic counseling traces back to Sweden in the 1940s, although the term "genetic counseling" was not yet coined at that time. Nevertheless, the healthcare services provided constituted what we now recognize as genetic counseling activities. This process aims to assist individuals or families in understanding and managing the disease, prognosis, genetic basis, likelihood of recurrence, treatment options, or genetic testing possibilities, aiding them in making informed choices tailored to their condition and family circumstances (Setiawan et al,. 2020). However, genetic counseling interventions conducted in hospitals and other healthcare services are still considered inadequate. Several studies have shown patient dissatisfaction with the treatment of genetic diseases provided in healthcare facilities. Furthermore, the roles and responsibilities of healthcare providers in caring for patients with genetic diseases have not been well identified. Therefore, researchers are striving to utilize long-distance technology as a communication tool in addressing these issues (Setiawan et al,. 2024).

The utilization of information technology to support healthcare services and treatment management can take various forms, including telehealth, web-based platforms, telephone consultations, or mobile applications. Technology enables healthcare services and treatments to be delivered remotely, facilitating the development of new interventions tailored to patient needs. This means that patients and healthcare providers do not necessarily meet face-to-face but interact through available media accessible to patients and their families. Technological practices can be applied across various domains of care, including technology for emergencies and outpatient care, call center services, and discharge planning. Several developed countries have implemented remote technology in the management of patient care for genetic disorders. There exists a review on the impact of social support on the quality of life of thalassemia patients. This review assesses the effectiveness of interventions for thalassemia patients and identifies promising findings to enhance the quality of life of thalassemia patients through social support Greco (2022).

The previous systematic review by Rodigari et al,. (2022) provided psychological intervention programs for thalassemia patients. The results of this review demonstrated that such interventions had a significant impact on improving the quality of life in children with thalassemia. However, both reviews focused

solely on one type of disease, namely thalassemia. Therefore, a systematic review on the effectiveness of remote technology interventions is yet to be found, providing a better understanding of such interventions. Researchers have adopted a systematic review approach to assess the effectiveness of remote technology in addressing psychological problems in patients with genetic disorders.

LITERATURE REVIEW

The definition of psychoeducation in the Indonesian Psychology Code of Ethics is an activity carried out to increase understanding or skills as an effort to prevent the emergence of psychological disorders and to increase understanding for the community, especially families, about psychological disorders (HIMPSI, 2010). Psychoeducation is a systematic, structured intervention to convey knowledge about illness and its treatment by integrating emotional and motivational aspects to enable patients to overcome their illness. Psychoeducation is an important component of treating medical and psychiatric disorders, especially mental disorders related to lack of insight. The content of psychoeducation is the etiology of an illness, the therapy process, side effects of medication, coping strategies, family education, and life skills training.

Psychoeducation is basically open to anyone, including children, teenagers and adults, individually or in groups. 10 The implementation of psychoeducation is divided into 3 service areas to facilitate the intended targets, namely: 1) Psychoeducation in the school environment targeting students. 2) Psychoeducation in industrial and organizational environments for employees. 3) Psychoeducation in the community environment for the wider community (Supratikya, 2011). b. Psychoeducational Focus Walsh concluded that the focus of psychoeducation based on the definition of psychoeducation is as follows: 1. Educating participants about life's challenges. 2. Help participants develop sources of support and social support in facing life challenges. 3. Develop coping skills to face life's challenges. 4. Develop emotional support. 5. Reduce participants' sense of stigma. 6. Changing participants' attitudes and beliefs towards a disorder. 7. Identify and explore feelings about an issue (Walsh, 2010).

METHODS RESEARCH

Reporting of the item selection for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline forms the basis of this study. To be included in this review, articles must have been published in English with open access and full-text availability in their original form from 2012 to 2023. The participants or population (P) of this study are patients with genetic disorders receiving technology-based psychoeducation and genetic counseling interventions (I). The outcome (O) is psychosocial problems. The study design (S) includes Randomized Controlled Trials and quasi-experimental research. Exclusion criteria include patients with mental health issues, literature review articles, systematic reviews, and umbrella reviews. Several journal databases, including PubMed, Scopus, Wiley Online Library, and ProQuest, were searched using advanced search engine techniques with the following keywords:

Table 1. Keywords

Data based	Search strategy	Result
Scopus	“patients with genetic problems” AND “remote technology” OR telephone AND “psychosocial problems” AND “randomized controlled trial”	1.153
PubMed	((((("remote technology "[Mesh]) AND "website"[Mesh]) OR "psychoeducation"[Mesh]) AND "psychosocial problems"[Mesh]) AND "Randomized Controlled Trial"	379
ProQuest	patients with genetic problems AND (telemedicine) OR (telehealth) AND (psychosocial problems) AND (randomized controlled trial)	83
Wiley	"patients with genetic problems" AND "genetic counselling" AND "quality of life" AND "Randomized controlled trial"	47

The selection of relevant studies was guided by the PIOS framework to determine specific eligibility criteria. The population consisted of adults with genetic disorders. In this study, the intervention was compared with standard care, defined as face-to-face consultations with doctors or nurses and excluding any form of education via remote technology. The intervention comprised psychoeducation and remote genetic counseling led by counselors, defined as the provision of genetic counseling or ongoing guidance regarding individual health management through mobile apps, the internet, web-based platforms, or mobile phones coordinated and delivered by counselors. After searching for previous articles in the EndNote X9 bibliographic software entry and removing duplicates, two assessors independently selected titles and abstracts of articles. Further analysis was conducted on the selected article abstracts. If there were doubts about whether a research article should be included in the second round of selection, the authors reviewed the entire article. If necessary, discrepancies were resolved by discussing with another assessor. The methodological quality of relevant studies was independently assessed through two reviews using the Joanna Briggs Institute (JBI) critical evaluation methodology for evaluating the efficacy of data reporting. For each study, reviewers assigned "yes," "no," "unclear," or "not applicable" for each critical criterion of the assessment tool. Based on Heratanti et al. (2021), we categorized quality. The total score was calculated as the percentage of "yes" responses in the critical appraisal outcomes using the JBI tool. A checklist for randomized controlled trials to be included in the data extraction table was provided with a minimum score of 9 (70% of the total

score of 13). During the research quality assessment process, discrepancies could be resolved by discussing with another reviewer if necessary.

RESEARCH RESULT

The journal database yielded 1,662 articles. After removing duplicates, examining titles and abstracts, and checking full texts, 11 articles were selected. Researchers then conducted quality assessment on the 11 articles; one article with a score below 70% was excluded, and 10 articles meeting the inclusion criteria were included in the systematic review (Fig. 1).

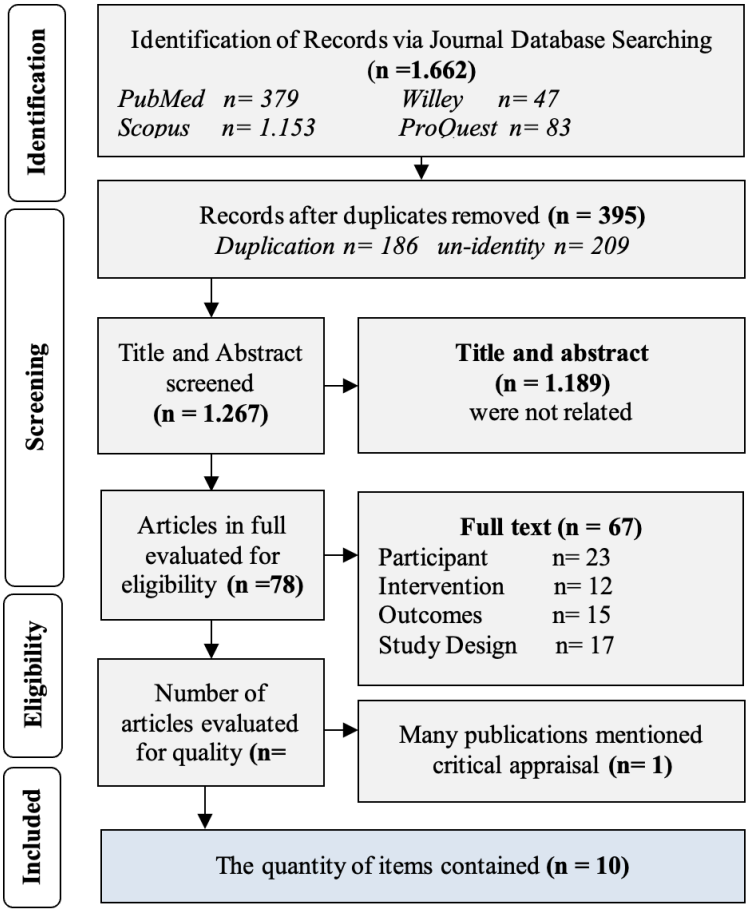

Figure 1. PRISMA flowchart

Table 2 illustrates the detailed characteristics of the studies. The total number of study subjects is 2,413 individuals, with 1,203 individuals in the intervention group and 1,210 individuals in the control group. The results of the research in the intervention group indicate an improvement in the quality of life of patients. There are 10 articles in this review, 8 articles on cancer, and 2 articles on thalassemia. The included studies encompass various developed countries: the United States (n=6), Iran (n=2), and Korea (n=2). Psychoeducation and genetic counseling interventions utilized information technology such as telephone, web-based platforms, and mobile applications. Counseling sessions varied between 1-6

sessions, with durations of 20-50 minutes. All interventions were reported to be significantly effective in improving psychological issues, thereby enhancing the quality of life of patients, and the timing of outcome measurement varied from one to twelve months.

DISCUSSION

This review examines how technology-based psychoeducation and genetic counseling can improve the quality of life of patients with genetic issues. Analysis and synthesis were conducted on ten studies to assess the impact of interventions. Our review demonstrates a significant improvement in the quality of life of patients after the intervention. This suggests that the use of technology can address the psychological issues of patients with genetic problems.

Table 2. Data extraction

Author (year) country	Design	Disease types	Purpose	Intervention	Control group	Measurement Tools	Outcome
(Yun et al., 2012) korea	RCT	Cancer Stadium 1-3	To determine the effectiveness of web-based psychoeducation programs on fatigue in cancer patients.	Web-Based Intervention: Provided by professionals over 12 weeks via structured guidelines covering energy conservation, physical activity, nutrition, sleep hygiene, pain control, and distress management.	Standard care	Brief Fatigue Inventory (BFI), Hospital Anxiety and Depression Scale (HADS) and (EORTC QLQ-C30)	In the intervention group, a psychoeducational intervention utilizing web-based platforms resulted in increases in quality of life scores, as well as reductions in anxiety and tiredness.
(Kinney et al., 2014) US	RCT	Breast and ovarium cancer	To improve the psychosocial status of breast cancer patients.	Telephone-based Intervention: Conducted by five genetic counselors using a semi-structured protocol.	Face-to-face counseling	Brief Symptom Inventory (BSI), Impact of Event Scale (IES)	Genetic counseling intervention via telephone proved effective in alleviating

				Participants opened guides during sessions, and counselors used visual aids to explain breast-ovarian genetic diseases. Counseling sessions lasted 20 minutes each, conducted once via telephone. Pretest measurements were taken one week after.			anxiety and distress.
Mare 2014 US	RCT	Breast and ovarium cancer	To examine whether the delivery of genetic counseling for BRCA1/2 via telephone is not inferior to face-to-face delivery.	Telephone-based Intervention: Delivered directly by certified/suitable genetic counselors once patients received DNA test results.	Usual care	Breast Cancer Genetic Counseling Knowledge, Decisional Conflict Scale (DCS), Genetic Counseling Satisfaction Scale (GCSS), Short Formulir-12 (SF-12)	Telephone-based genetic counseling was no less effective than face-to-face delivery in all primary outcomes.
(K. Ashing & Rosales, 2014) US	RCT	Breast cancer	To investigate the impact of telephone-based psychoeducation intervention on depression	Telephone-based Intervention: Lasting 40 minutes per session, conducted eight times biweekly. Psychoeducation materials covered	Usual care	Center for Epidemiological Studies Depression scale (CES-D), Functional Assessment of Cancer	Overall trial results showed statistical significance in decreasing depression symptoms among breast cancer

			symptoms in breast cancer patients.	disease basics, self-care, coping exercises, stress management, and social support.		Therapy (FACT)	patients compared to patients in the control group.
(Lee et al., 2014) korea	RCT	Cancer stadium 1-4	To reduce suffering in cancer patients.	Tablet PC-Based Intervention: Adapted from HY Park's material, delivered via 20-minute PowerPoint slide videos consisting of four parts: hardship education (vulnerability, definition, common symptoms), cancer survivor interviews, coping strategies and stress management, and psychosocial services.	Standard care	Hospital Anxiety and Depression Scale (HADS), Insomnia Severity Index, Impact of Event Scale-Revised (IES-R)	Psychoeducation using PC tablets during chemotherapy infusion may be a useful intervention for cancer patients' sadness, sleep issues, and overall quality of life.
(Laurel Northouse, 2014) US	Feasibility study	Pulmonal, breast, colorectal cancer, and prostat	To assess the initial impact of web-based interventions on patient and caregiver outcomes, examine participant program satisfacti	Website-Based Intervention: Conducted by professionals over three sessions within six weeks, covering family involvement, optimistic perspectives, coping effectiveness, uncertainty reduction, and	Standard care	Functional Assessment of Cancer Therapy (FACT-G). Emotional distress was measured with the 30-item	The results showed a considerable sense of greater advantages from disease and caring, as well as a decrease in emotional discomfort and an improvement in

			on, and evaluate telephone-based psychoeducation interventions.	symptom management.			quality of life. Additionally, caregivers' self-efficacy significantly increased.
(K. T. Ashing & Miller, 2016) US	RCT	Breast cancer	To enhance the HRQOL outcomes of breast cancer patients.	Telephone-based Intervention: Conducted over eight biweekly sessions lasting 40 to 50 minutes each, covering breast cancer basics, medical and physical problem management, problem-solving, medical communication skills, emotional balance, stress management, family and social support.	Routine care	Health-Related Quality of Life (HRQOL)	Regression analysis results indicated that telephone-based psychoeducation interventions significantly influenced HRQOL.
(Bradbury et al., 2018) US	RCT	Cancer	To increase knowledge and assess anxiety status.	Telephone-based Intervention: Communication protocols and visual aids were standardized. All sessions were recorded. Counseling sessions conducted twice via telephone.	Usual care	Hospital Anxiety and Depression Scale (HADS)	Patients who had favorable results in the subgroup analysis saw a statistically significant decrease in overall anxiety within the intervention group.

(Gharaati et al., 2019) iran	Quasi eksperimen	Thalasemia mayor	To explore the impact of an education intervention via mobile phone on self-care behaviors of major thalassemia patients.	Telephone-based Intervention: Six calls lasting 15-18 minutes monthly covering disease, medication adherence, thalassemia side effects, nutritional management, physical activity, and smoking cessation.	Standard care	Instrument was a questionnaire developed by the researcher which comprised four sections	The findings show that patients with thalassemia had improvements in their self-care practices following an educational intervention using mobile phones.
(Kharaman et al 2023) iran	Quasi eksperimen	Thalasemia	To compare the effects of self-care education through a smartphone application and lectures on the self-efficacy of thalassemia patients.	Mobile Application-Based Intervention: Conducted biweekly over eight weeks, covering dietary patterns, smoking effects, importance of physical activity, iron utilization, blood transfusion importance, psychological and social issues related to thalassemia.	Explanation education	General Self-Efficacy Scale	When thalassemia patients received self-care education via smartphone applications, their mean self-efficacy ratings increased significantly to 68.36 (8.45) from 62.55 (7.3) when they received lecture instruction.

The ten included studies show positive results in addressing psychological issues post-intervention. The interventions provided were related to psychoeducation and genetic counseling, monitoring patients' physical activity, medication adherence, vital sign monitoring, and providing information to enhance health literacy and decision-making (Estria & Nurjanah, 2020).

Remote monitoring is conducted virtually, allowing patients to access it from a distance.

Technology can support changes in health behavior, and through m-health applications, it can provide better understanding of the patient's condition. Patient physical activity monitoring is increasingly improving with the assistance of applications, yet further research is needed to determine the concentration of patient physical activity (Tuba et al,. 2023)

Our review found that telehealth has a positive impact on the quality of life of patients. One of the included studies indicated that patients frequently accessed health behavior education-themed content, and there was an improvement in health behavior after using m-health, consistent with findings from previous systematic reviews showing that improved health behavior leads to increased quality of life. However, the use of telehealth should be considered as a complementary intervention alongside direct nursing interventions. Instruments used to assess patient outcomes include quality of life, anxiety, depression, self-care, and other outcomes.

Quality of Life

Quality of life was measured by European Organization for Research and Treatment of Cancer (EORTCQoL C30), Short Form-36 (SF-36), the Functional Assessment of Cancer Therapy (FACT), and health-related quality (HRQoL). EORTCQoL C30, measurement instrument developed by the European Organization for Research and Treatment of Cancer (EORTCQoL C30). The global health status, physical, role, emotional, cognitive, and social functioning are all measured on this 30-item questionnaire; high scores indicate a good quality of life. Additionally, the questionnaire asks about symptoms associated to cancer. This study's results demonstrated that a web-based intervention significantly improved quality of life, as measured by a value of (5.22; 95% CI, 0.93 to 9.50) (Yun et al., 2012).

SF-36 measuring instrument To measure quality of life, this instrument assesses eight dimensions: physical function, bodily pain, social function, limited role due to physical problems, limited role emotional problems, mental health, energy/vitality and general health perception. The results of this study show that telephone intervention has been proven to significantly improve QoL in breast cancer patients with a value of (ρvalue=0.001).

The Functional Assessment of Cancer Therapy (FACT) questionnaire contains 27 items designed to measure four HRQOL domains in cancer patients: Physical, social, emotional, and functional well-being. The research results showed that after being given Telephone-based Intervention the patient's quality of life increased by a value ($p < 0.01$). The FACT instrument was also used by Laurel Northo (2014) showing results that the quality of life of cancer patients increased after being given psychoeducational intervention.

The physical, psychological, and social health domain of health-related quality of life, or HRQOL, is one that is impacted by an individual's experiences, beliefs, hopes, and perceptions. The study's findings demonstrated that, following a telephone-based intervention, breast cancer patients' quality of life increased ($p < 0.05$).

Anxiety, depression and distress

Unfavourable psychosocial state such anxiety, depression, and distress was measured by Hospital Anxiety and Depression Scale (HADS), Brief Symptom Inventory (BSI)-18, the Epidemiological Studies

Center Depression Measure (CES-D), and the Impact of Event Scale (IES). The 14-item Hospital Anxiety and Depression Scale (HADS), which measures the intensity and effect of pain using the Brief Pain Inventory, has seven items for anxiety and seven for depression. The results of the study showed that after being given the Web-Based Intervention intervention, cancer patients experienced a decrease in their scores HADS anxiety was much greater (0.90; 95% CI, 1.51 to 0.29). The HADS instrument also conducted by Lee et al (2014) showed results that there was a change in the HADS depression subscale score (U = 69.0; p = 0.006). The HADS instrument was also used by Bradbury et al (2018) research which showed that after being given Telephone-based Intervention there was a change in the HADS depression subscale score (p = 0.02).

A measurement instrument called the Brief Symptom Inventory (BSI)-18. Six anxiety-related symptoms are used to compute the anxiety subscale. possible scores are (0–24). Higher scores indicate greater anxiety. The research results showed that after the Telephone-based Intervention there was a decrease in anxiety levels with a mean value (95% CI) of 12.9 (11.6 to 14.2) (Kinney et al., 2014).

The Epidemiological Studies Center Depression Measure The CES-D 20-item measure was employed to evaluate symptoms of depression. There is a four-point rating system for items. Higher scores are indicative of depression symptoms. The research results showed that after being given Telephone-based Intervention, the patient's depression level decreased by a value ($p < 0.05$) (K. Ashing & Rosales, 2014).

Distress related to cancer was scored at each evaluation using the Impact of Event Scale (IES), which has a potential score range of 0 to 75. The willingness of individuals to experience intrusive thoughts regarding their history of cancer was tested by these fifteen questionnaires. Higher scores correspond to more discomfort related to cancer (Kinney et al., 2014).

Other outcomes

Cancer-related tiredness is measured using the Brief tiredness Inventory (BFI) measurement instrument. Each of the nine items in the BFI rates the degree of tiredness on a range from 0 to 10. The initial trio of questions evaluates the level of exhaustion both now and during the last 24 hours. The next six inquiries evaluate the extent to which weariness impeded different facets of life, such employment or interpersonal connections, during the course of the preceding 24 hours. The Web-Based Intervention intervention, with a global BFI value of 0.66 points; 95% CI 1.04 to 0.27, demonstrated a reduction in tiredness levels among cancer patients, according to the intervention's outcomes (Yun et al., 2012).

The instrument was a four-section questionnaire that the researcher created. There are twenty questions covering topics such as the patient's knowledge of the illness and its side effects, self-care practices, chelation therapy, blood injections, the illness's repercussions, and suggested courses of treatment. After receiving telephone-based intervention, there was a statistically significant increase in the intervention group's knowledge scores, attitudes, and self-care behavior (Gharaati et al., 2019)

General Self-Efficacy Scale, It is divided into three sections:

patient awareness, self-care practices, and demographic traits and background information on thalassemia patients. Answers to the question about active consciousness are "True," "False," or "I don't know." "True" receives a score of 1, while "False" and "I don't know" receive zeros each. The findings demonstrated that following the intervention, there was a significant change in the three groups' levels of self-efficacy (P=0.001) (Kharaman et al 2023).

CONCLUSION

Remote genetic counseling and psychoeducational interventions have been proven to improve psychological issues in patients with genetic problems, as determined by the findings of this review. Similar to the synthesis of reviews showing positive results in enhancing psychological issues, thus improving the quality of life of patients. Although the quality of evidence ranges from moderate to high, the results should be cautiously considered because standardization of technology-based interventions in terms of frequency and content still varies. Further standardization of remote genetic counseling and psychoeducational interventions is needed to investigate the impact of interventions.

Source of funding

Kementerian Pendidikan, Kebudayaan, Riset dan Teknologi via Direktorat Jenderal Pendidikan Vokasi with contract number 101/SPK/D.D4/PPK.01.APTV/III/2024; 009/SP2H/RT-MONO/LL4/2024; 31/III.3.AU/D/2024

Conflict of interest

There is no conflict of interest.

Ethical approval

This research was approved by Health Research Ethics Committee, STIKes Muhammadiyah Ciamis in March 25, 2024 with the number 021/KEPK-STIKESMUCIS/III/2024.

Authors contributions

Each author contributed equally in all the parts of the research. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

REFERENCES

Alshaya, D. S. (2022). Genetic and epigenetic factors associated with depression: An updated overview. Saudi Journal of Biological Sciences, 29(8), 103311. https://doi.org/10.1016/j.sjbs.2022.103311

Ashing, K., & Rosales, M. (2014). A telephonic-based trial to reduce depressive symptoms among Latina breast cancer survivors. Psycho-Oncology, 23(5),507515.https://doi.org/10.1002/pon.3441

Ashing, K. T., & Miller, A. M. (2016). Assessing the utility of a telephonically delivered psychoeducational intervention to improve health-related quality of life in African American breast cancer survivors: A pilot trial. Psycho-Oncology, 25(2), 236–238.https://doi.org/10.1002/pon.3823

Biesecker, B. (2020). Genetic counseling and the central tenets of practice. Cold Spring Harbor Perspectives in Medicine, 10(3), 1–11. https://doi.org/10.1101/cshperspect.a038968

Bradbury, A. R., Patrick-Miller, L. J., Egleston, B. L., Hall, M. J., Domchek, S. M., Daly, M. B., … Yao, X. S. (2018). Randomized noninferiority trial of telephone vs in-person disclosure of germline cancer genetic test results. Journal of the National Cancer Institute, 110(9),985993.https://doi.org/10.1093/jnci/djy015

El-Baky, R. M. A., Ibrahim, R. A., Mohamed, D. S., Ahmed, E. F., & Hashem, Z. S. (2020). Prevalence of virulence genes and their association with antimicrobial resistance among pathogenic E. Coli isolated from egyptian patients with different clinical infections. Infection and Drug Resistance, 13, 1221–1236. https://doi.org/10.2147/IDR.S241073

Estria, S. R., & Nurjanah, S. (2020). Pengaruh Intervensi Psikoedukasi Berbasis Audio Visual Terhadap Internet Addiction. Keperawatan Muhammadiyah, 5(1), 85–95. Retrievedfromhttps://journal.umsurabaya.ac.id/JKM/article/view/3567

Gharaati, F., Aghamolaei, T., Hosseini, Z., Davoodi, S. H., Hassani, L., Mohamadi, R., … Soleimani-Ahmadi, M. (2019). Effect of a Mobile-Phone Mediated Based Education on Self-Care Behaviors of Patients with Thalassemia Major. Journal of Caring Sciences, 8(3), 149–155. https://doi.org/10.15171/jcs.2019.022

Greco, F., & Marino, F. (2022). Social Impact and Quality of Life of Patients with β-Thalassaemia: A Systematic Review. EMJ Hematology. https://doi.org/10.33590/emjhematol/22-00041

Kharaman-nia, F., Rezaei, H., Roustaei, N., Etemadfar, P., & Hosseini, N. (2023). Comparing the effects of self- care education by lecture and smartphone application on self-efficacy of patients with thalassemia. BMC Medical Informatics and Decision Making, 23(1), 1–9. https://doi.org/10.1186/s12911-023-02097-4

Kinney, A. Y., Butler, K. M., Schwartz, M. D., Mandelblatt, J. S., Boucher, K. M., Pappas, L. M., … Campo, R. A. (2014). Expanding access to BRCA1/2 genetic counseling with telephone delivery: A cluster randomized trial. Journal of the National Cancer Institute, 106(12), 21–28. https://doi.org/10.1093/jnci/dju328

Laksono, S. P., Qomariyah, & Purwaningsih, E. (2011). Persentase Distribusi Penyakit Genetik dan Penyakit. Majalah Kesehatan PharmaMedika, 13(2), 267–271. Retrieved from https://core.ac.uk/download/pdf/229000921.pdf

Laurel Northouse. (2014). A Tailored Web-Based Psycho-Educational Intervention for Cancer Patients and Their Family Caregivers. Bone, 23(1), 1–7. https://doi.org/10.1097/NCC.0000000000000159.A

Lee, J. Y., Jung, D., Moon, M., Keam, B., Park, H. Y., & Hahm, B. J. (2014). Effect of brief psychoeducation using tablet PC on depression and quality of life in distressed patients during chemotherapy: A pilot study. Psycho-Oncology, 22(February), 261. Retrieved fromhttp://www.embase.com/search/results?subaction=viewrecord&from=export&id=L71356818

Loveall, S. J., Hawthorne, K., & Gaines, M. (2021). A meta-analysis of prosody in autism, Williams syndrome, and Down syndrome. Journal of Communication Disorders, 89(October 2020), 106055. https://doi.org/10.1016/j.jcomdis.2020.106055

Nguengang Wakap, S., Lambert, D. M., Olry, A., Rodwell, C., Gueydan, C., Lanneau, V., … Rath, A. (2020). Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. European Journal of Human Genetics, 28(2),165173.https://doi.org/10.1038/s41431-019-0508-0

Rodigari, F., Brugnera, G., & Colombatti, R. (2022). Health-related quality of life in hemoglobinopathies: A systematic review from a global perspective. Frontiers in Pediatrics, 10(August), 1–14. https://doi.org/10.3389/fped.2022.886674

Senaldi, L., & Smith-Raska, M. (2020). Evidence for germline non-genetic inheritance of human phenotypes and diseases. Clinical Epigenetics, 12(1), 1–12. https://doi.org/10.1186/s13148-020-00929-y

Setiawan, H., Firmansyah, A., & Purwati, A. E. (2024). Integration of genomic nursing innursing education curriculum in Indonesia: A perspective. Journal of Taibah University MedicalSciences,19(2),250251. https://doi.org/10.1016/j.jtumed.2023.12.001

Setiawan, H., Roslianti, E., & Firmansyah, A. (2020). Theory DevelopmentofGeneticCounseling among Patient with GeneticDiseases. International Journal of Nursing Science and Health Services, 3(6), 709–715. https://doi.org/http://doi.org.10.35654/ijnhs.v3i6.350 Abstract.

Sosiawan, A., Kurniati, M., Danudiningrat, C. P., Wahjuningrum, D. A., & Mulyawan, I. (2021). The role of family history as a risk factor for non-syndromic cleft lip and/or palate with multifactorial inheritance. Dental Journal, 54(2), 108–112.https://doi.org/10.20473/J.DJMKG.V54.I2.P108-112

Tuba Arpaci, Naime Altay, G. Y. C. (2023). Evaluation of the Effectiveness of a Technology-Based Psychosocial Education and Counseling Program for Adolescent Survivors of Childhood Leukemia. Cancer Nursing, 46(1). https://doi.org/10.1097/NCC.0000000000001091

Yahaya, T. O., Oladele, E. O., Anyebe, D., Obi, C., Bunza, M. D. A., Sulaiman, R., & Liman, U. U. (2021). Chromosomal abnormalities predisposing to infertility, testing, and management: a narrative review. Bulletin of the National Research Centre, 45(1).https://doi.org/10.1186/s42269-021-00523-z

Yun, Y. H., Lee, K. S., Kim, Y. W., Park, S. Y., Lee, E. S., Noh, D. Y., … Park, S. (2012). Web-based tailored education program for disease-free cancer survivors with cancer-related fatigue: A randomized controlled trial. Journal of Clinical Oncology, 30(12), 12961303.https://doi.org/10.1200/JCO.2011.37.2979