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International Journal of Current Research
Vol. 9, Issue, 12, pp.62860-62866, December, 2017

INTERNATIONAL JOURNAL OF CURRENT RESEARCH

ISSN: 0975-833X

RESEARCH ARTICLE

IDENTIFYING STRATEGIES TO HELP IMPROVE HEALTH-RELATED QUALITY OF LIFE OF CHILDREN WITH SICKLE CELL DISEASE

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ARTICLE INFO

Article History:
Received 13th September, 2017
Received in revised form
20th October, 2017
Accepted 22nd November, 2017
Published online 27th December, 2017

Key words:
Strategies,
HRQOL,
Sickle cell disease.

ABSTRACT

Problem: Sickle cell disease is an inherited, chronic hematological disorder, which under certain conditions changes the red blood cells to sickle-shaped cells due to an abnormality in the hemoglobin. It is associated with profound complications that affect different organ systems. Due to the complex nature of this disease, sickle cell disease significantly affects children's overall health. This, in fact, suggests the need to assess all health domains in order to improve the health related quality of life for children with sickle cell disease. The aim of this review is to identify strategies that help to improve health- related quality of life of children with sickle cell disease.

Methodological approach: A literature review was conducted using multimodal search strategy of multiple databases that include CINAHL, Medline, PubMed, Science Direct, Psych Info, SCOPUS, and Web of Science. This review covers the period between 1995 and 2015.

Finding and Conclusion: Sixteen articles were retrieved. The literature suggested that educational and cognitive behavior therapy interventions improved various aspects of health. This review found that both interventions were helpful in improving the participants' knowledge about the disease and increasing their ability to manage their disease symptoms, thus improving the physical, mental and cognitive aspects of health.

Citation: Dr. Yusra Al Nasiri, Dr. Adhra Al Mawali and Dr. Eufemia Jacob, 2017. "Identifying strategies to help improve health-related quality of life of children with sickle cell disease", *International Journal of Current Research*, 9, (12), 62860-62866.

INTRODUCTION

Sickle cell disease (SCD) is an inherited, chronic hematological disorder, which under certain conditions changes the red blood cells to sickle-shaped cells due to an abnormality in the hemoglobin (Stuart and Nagel, 2004). It is associated with profound complications that affect different organ systems (Brousse *et al*., 2014; Wrotriak *et al*., 2012). Frequent painful crises, infections, stroke, acute chest syndrome, splenic sequestrations, priapism, and organ failures are the most common complications affecting children with SCD (Stuart and Nagel, 2004). As a genetic hematological disorder, SCD affects children worldwide and it contributes to high morbidity and mortality rates specifically in children under the age of 5 (World Health Organization, 2010). The World Health Organization (WHO, 2010) stated that SCD is a global epidemic and approximately 300,000 babies are born with this disease worldwide annually; of those an estimated 100,000 births are in the United States. According to the Centers for Disease Control and Prevention (CDC) statistics, SCD is prevalent in 1 out of 500 African Americans and in about 1 out of 36,000 Hispanic Americans. Although SCD seems to be higher in children of African descent, an increasing number of SCD cases have been observed in mixed race individuals (Brousse *et al*., 2014). WHO (2010) stressed that SCD remains a global concern; therefore, different strategies must be established to limit early mortality from the disease. Furthermore, WHO has suggested that careful evaluation to improve the quality of life (QOL) for children with SCD is a priority. Due to the complex nature of this disease and its life threatening-complications, SCD significantly affects children's overall health. This, in fact, suggests the need to assess all health domains in order to improve the quality of life for children with SCD (Makani, Ofori, &ONnodu, 2013; Thornburg, Dixon, &Burgett, 2009). Health-related quality of life(HRQOL) has become an important outcome in much research since it focuses on specific health domains related to physical, mental, emotional, and social functioning (Ferrans, 2005, Panipinto, Torres, &Verni, 2012; Verni, Burwinkle, & Katz, 2002). Unfortunately, management of SCD is still challenging not only for hematologists but also for the affected children and their parents (Wright, Thomas, &Serjeant, 2008). Despite the advancements in SCD treatment that have occurred over the past 10 years (Wright *et al*., 2008), the HRQOL for children with SCD remains poor. Thus, improving their HRQOL is deemed a priority (WHO, 2013).

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Search Strategy

A comprehensive search strategy was carried out to identify the relevant published and unpublished articles in all major databases, including CINAHL, Google Scholar, PubMed, PsychINFO, ERIC, SCOPUS, and Web of Science. There is an apparent paucity of literature on the strategies for improving HRQOL in children with SCD. Hence, this review covers the period between 1995 and 2015. In order to capture all materials germane to the review, a four-step search strategy was devised using various keywords and terminologies. Initially, a limited search of the PubMed and CINAHL databases was undertaken to obtain different keywords. Second, a comprehensive search was conducted of all major databases, including MEDLINE, CINAHL, ERIC, PubMed, PsychINFO, Google Scholar, and SCOPUS, using general keywords (Sickle Cell Disease, SCD, Health-Related Quality of Life, HRQOL, pediatric, children, interventions, and strategies). In the third step, a search builder was utilized and a combined search strategy was conducted in which different outcomes and interventions were included (Sickle Cell Disease or SCD or sickle-cell disorder, interventions or strategies, pediatric or children, HRQOL, Health-Related Quality of Life or physical dimension or mental dimension or cognitive dimension or social dimension or psychological dimension or psychosocial dimension). Step four involved checking the references of the retrieved articles for any new articles relevant to the review. The initial search yielded 78 articles. After checking the retrieved articles against the inclusion and exclusion criteria (Table 1), 24 articles were selected. From the combined searches, fivearticles were retrieved and after checking those articles against the inclusion and exclusion criteria, one article was chosen. Therefore, from the initial and combined searches, a total 25 articles were retrieved, duplicates were removed and, consequently, a net total of 16 articles were found (Figure 1) to meet the inclusion and exclusion criteria of this review (Table 1). No article was retrieved from the fourth step, which involved checking the references for new articles.

Summary of the Articles

Sixteen articles were retrieved for this review; 14 articles presented data on studies conducted in the United States, one article presented data on a study conducted in the United Kingdom, and one article presented data on a study conducted in Lebanon (Table 2). The majority of the participants in those studies were African Americans (Table 2).

Literature Review

The most common interventions that emerged from the literature were educational interventions and Cognitive Behavior Therapy (CBT) interventions. Therefore, this paper will be structured based on themes that reflect thetwo types of interventions utilized in those studies.

Educational Intervention

Six articles (Frei-Jones, Field, & DeBaun, 2009; Hazzard, Celano, Collins, & Markov, 2002; Hines, Crosby, Johnson, Valenzuela, Kalinyak, Joiner, 2011;Mahat, Scoloveno, Barnette, & Donnelly, 2007; Reagan, Michael, DeBaun, &Frei-Jones, 2011; Shahine, Kurdahi, Karam, Abboud, (2015) utilized educational intervention (an educational teaching session by the researchers) in order to increase knowledge about the disease, enhance management of SCD symptoms, and improve coping strategies among children with SCD. All of these studies aimed to evaluate the effectiveness of this intervention on different health outcomes, which included symptoms management, improving coping skills, and reducing hospitalization. All of the studies reached similar findings that educational intervention improved the parents' and children's knowledge about SCD and symptoms management and reduced the hospitalization rate. Two studies (Mahat *et al*., 2007; Shahine *et al*., 2015) utilized educational sessions, which were delivered by the researchers to the parents of children with SCD. Shahine *et al*. (2015) utilized pre-posttest designs and their findings revealed that after the intervention both the caregiver's knowledge about SCD and their symptoms management were significantly increased ($P= 0.001$) and the rate of re-admission was significantly decreased ($P< 0.05$).

Mahat *et al*. (2007) reached the same conclusions utilizing a survey design. The findings from that study revealed that the parents' knowledge about the disease and symptoms management increased after they participated in educational sessions that were conducted over the course of three days. Using a written educational guide (consisting of information about SCD, symptoms, and management), Hines *et al*. (2011) found that parents' knowledge about the disease and managing its symptoms at home were improved after a two-month period due to having used the guide. In that study, a questionnaire was used to assess improvement in controlling SCD symptoms. Similar findings were obtained by Frei-Jones *et al*. (2009) and Reagan *et al*. (2011) utilizing a multi-intervention strategy that consisted of educational sessions along with a standardizing pain medication order. Both studies utilized a pre-posttest design and the findings revealed that the intervention was successful in reducing the frequent re-admission rate of children with SCD; the intervention also improved treatment adherence among the participants. Education was the strongest component of this intervention model. It led to improved symptoms management and treatment adherence, which in turn reduced the re-admission rate for children with SCD, 6 months and 12 months after the intervention. A consistent finding was obtained by Hazzard *et al*. (2002) utilizing a different method for education. That study used the STARBRIGHT computer program that included downloaded educational materials about SCD, symptoms management, training for a relaxation technique, media for social interaction, and educational games. The results revealed that the STARBRIGHT was effective and a significant difference ($P<0.001$) was noted in the level of knowledge about how to manage the symptoms of SCD, perceived social support, and coping skills among the intervention group as compared to the control group. The findings from the literature suggest that educational intervention is an effective strategy that helps improve children's and parents' knowledge about SCD, improves symptom management, and reducesthe re-admission rate. All of the studies had similar findings despite the type of educationalintervention that was used; however, the educational intervention delivered by a computer program was also found to improve social interaction, which was not reported in the studies that used other types of educational interventions.

Cognitive Behavior Therapy (CBT) Intervention

Cognitive Behavior Therapy (CBT) is another intervention that was reported in the reviewed literature.

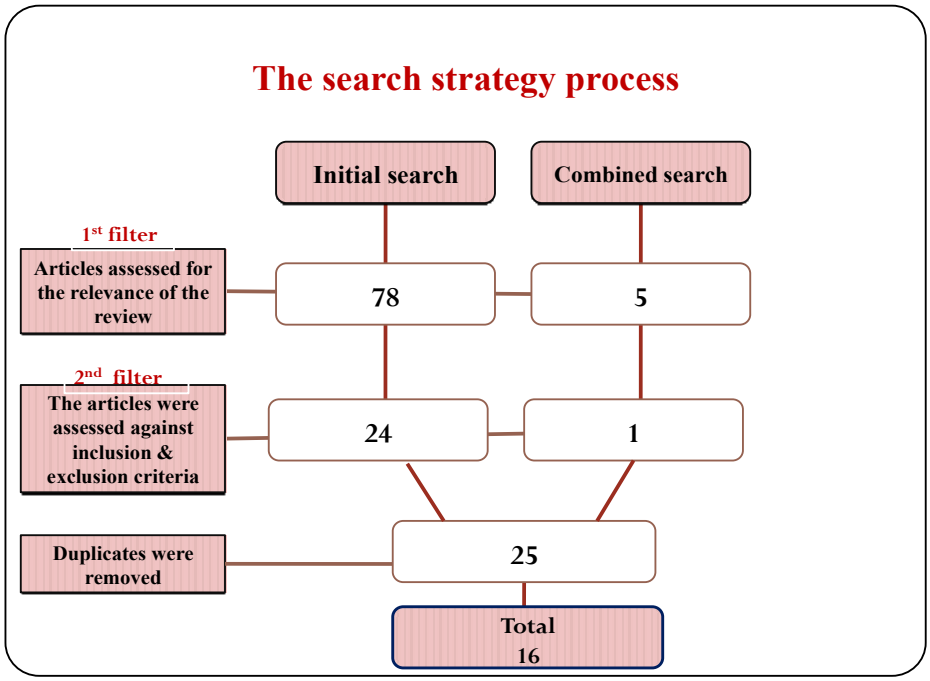

Figure 1. The search strategy results

Ten studies (Barakat, Schwartz, Salamon, & Radcliffe, 2010; Dines, Whitehouse, Orne, Bloom, Carlin, Bauer, & Gilen, 1997; Gil, Wilson, Edens, Workman, Ready, Sedway, Redding-Lallinger, &Daeschner, 1997; Gil, Anthony, Carson, Reddin-Lallinger, Daeschner, &War, 2001; Hicks, Baeyer, &McGrath, 2006; Kaslow, Collins, Rashid, Baskin, Griffith, Hollins, &Eckman, 2000; McClellan, Schatz, Sanchez, &Stancil, 2009; Powers, Mitchell, Graumlich, Byars, &Kalinyak, 2002; Schwartz, Radcliffe, &Barakat, 2007; Thomas, Dixon, &Milligan, 1999) utilized a CBT intervention to investigate if cognitive coping skills training would enhance pain coping strategies and alter pain perception in children with SCD. The interventions in those studies were nearly similar and consisted of a psycho-educational training session about coping strategies, such as deep breathing, counting, relaxation, pleasant imagery, and calming self-statements. The intervention period and the CBT training sessions varied in the reviewed studies (Table 2). Despite this variation, some of the studies had similar findings. Four studies (Gill *et al*., 2001; Kaslow *et al*., 2000; Powers *et al*., 1999; Thomas *et al*., 2002) utilized pre-post test designs and reported similar findings. Those studies indicated that CBT intervention improved the knowledge, coping skills, and management of disease symptoms at home for children with SCD and their caregivers. The follow up results done by these studies indicated that the caregivers and children were found to be more confident in their ability to control pain at home and their psychological status improved.

Gil *et al*. (1997) and Schwartz *et al*. (2007) used the same design (pre-post test); however, CBT intervention only improved the physical and cognitive functioning for the children with SCD. While both studies used questionnaires to collect data, Gil *et al*. (1997) also used a daily diary to measure pain. Unlike Gil *et al*. (1997) and Schwartz *et al*. (2007), Dines *et al*. (1997) found that the CBT intervention improved the physical and social aspects of health in children with SCD. The participants improved their ability to control their SCD symptoms and reduce their pain; however, 18 months following the intervention, the social life of the participants also improved. In addition, two studies (Hazzard *et al*., 2002; Hicks *et al*., 2006) used an innovative wireless technology for CBT training. The findings in both studies indicated that CBT improved symptoms management, reduced frequent pain crises andre-admissions and increased social interactions and self-efficacy. However, these studies had inconsistent findings regarding psychological improvement post-intervention. Hicks *et al*. (2006) found that 8 weeks after the intervention, the psychological dimension improved; whereas, Hazzard *et al*. (2002) concluded that the perceived coping ability of the participants had decreased in the post-intervention period, which lasted three days. Barakat *et al*. (2010) observed a different finding than the other studies using the same design. That study's findings indicated that CBT slightly improved the SCD knowledge and self-efficacy in adolescents and no significant difference (P>0.05) was noted between children with SCD and the control group in terms of psychosocial improvement. However, the treatment group showed some improvement in SCD knowledge and self-efficacy in the post test and also the 12-monthfollow up period. CBT wasfound to be an effective intervention method for improving different health outcomes in children with SCD. It was found that CBT improved the disease knowledge, coping skills, and management of symptoms at home for children with SCD and their caregivers. All of the studies had consistent findings that CBT improved the physical aspect of health and that the intervention improved the participants' confidence level in their ability to manage SCD symptoms. In regards to the cognitive and psychological aspects, the studies varied in their findings. Some studies reported that the intervention improved coping abilities and negative thinking was reduced. In addition, only the studies that used wireless technology for the CBT intervention found that CBT improved the social interactionsbetween families, health care providers, and other participants with a similar disease, which was not indicated in any of the other studies.

Critical analysis and synthesis

The findings in the literature review suggestthat educational interventions and CBT interventions are both effective

Table 1. Inclusion and Exclusion Criteria for the Selected Articles for the Literature Review

Inclusion Criteria	Exclusion Criteria
Studies published in English	Studies published in a language other than English
Research-based articles	Systematic review, literature review articles, conference papers
Studies done on children as a population	Studies done on adults
Peer-reviewed articles	Articles published before 1995

Table 2. Summary of the Reviewed Articles

Author	Setting	Sample	Ethnicity	Design	Intervention Period	Tool	Reliability	HRQOL Outcomes Post-Intervention			
								Physical	Emotional	Social	Cognitive
Shahine et al. (2015)	Lebanon	N=57 (CH) N=43 (PA)	Not indicated	Pre-Post test	2 months	Questionnaire	Adopted & translated to Arabic r=0.76	Improved	Not indicated	Not indicated	Not indicated
Fre-Jones et al. (2009)	United States	N= 68	Not indicated	Pre-Post test	6 months	Hospital computer record	Not indicated	Improved	Not indicated	Not indicated	Not indicated
Mahat et al. (2007)	United States	N=48	African American	Survey design	2 months	Questionnaire	Not indicated	Improved	Not indicated	Not indicated	Not indicated
Reagan et al. (2011)	United States	N=102	Not indicated	Pre-Post test	12 moths	Hospital computer record	Not indicated	Improved	Not indicated	Not indicated	Not indicated
Hines et al. (2011)	United States	N= 300	African American	Survey design	3 days	Questionnaire	Not indicated	Improved	Not indicated	Not indicated	Not indicated
Kaslow et al. (2012)	United States	N= 39	African American	Pre-Post test	6 weeks (6 CBT sessions)	Questionnaires SDKT ,CDI FACEII ,CBCL	SDKT (r= 0.72) CDI (r=o.86) FACEII (0.87) CBCL(reported as reliable).	Improved	Improved	Not indicated	Improved
Gill et al. (1997)	United States	N=49	African American	Pre-Post test	2 weeks (2 CBT sessions)	Daily diary CSQ (for coping)	Not indicated CSQ (reported as established in other studies)	Improved	Not indicated	Not indicated	Improved
Barakat et al. (2010)	United States	N= 49	African American	Pre-Post test	1 week & followed up at 12 months (1 week training session)	Questionnaires Self efficacy, Knowledge, Child's health	Self efficacy (r= 0.9) Child health (r= 0.6) Knowledge (r= not indicated)	Improved	No difference	No difference	Not indicated
McClellan et al. (2009)	United States	N=19	African American	Pre-Post test (Wireless technology	8 weeks (8 CBT sessions)	Electronic Daily Diary (device) connected to wireless technology	Not indicated	Improved	Improved	Improved	Not indicated
Hazzardet al. (2002)	United States	N=47	African American	Pre-Post test (Wireless technology)	During admission (3-5 day) 1 day session	Questionnaire for knowledge PSS-FR for social support Kidcope for coping Questionnaire for satisfaction	Adopted r=0.92 (Kaslow's research) The adolescent version of the questionnaire reported as having adequate reliability.	Improved	Decreased Negative coping increased)	Improved (Perceived social support improved)	Not indicated
Gill et al. (2001)	United States	N=46	African American	Pre-Post test	1 month (1 CBT session)	Daily Diary CSQ (for coping) RCMAS (for Anxiety) CDI (Depression)	Not indicated	Improved	Improved	Not indicated	Improved
Schwartz et. al (2007)	United States	N=25	African American	Pre-Post test	4 month (4 CBT)	Questionnaire	Reliability not indicated	Improved	Not indicated	Not indicated	Improved
Hicks et al (2006)	United States	N=47	Not indicated	Pre-Post test	7 weeks (7 CBT sessions)	Daily pain diary PedQL questionnaire	Reliability not indicated, PedQL (adopted r=0.95)	Improved	Improved	Improved	Not indicated
Powers et al. (2002)	United States	N=3	African American	Pre-Post test	8 weeks (6 CBT)	Daily Diary, CSQ	Not indicated	Improved	Improved	Not indicated	Improved
Thomas et al. (1999)	United Kingdom	N=59	West African & Afro-Caribbean	Pre-Post test	8 weeks (4 CBT)	GHO, CSQR, PSEQ, MPQ, BPCQ	Not indicated	Improved	Improved	Not indicated	Improved
Dines et al. (1997)	United States	N= 28	Not indicated	Prospective design	18 months (6 CBT)	Daily Diary	Not indicated	Improved	Not indicated	Improved	Not indicated

strategies that help improve different health outcomes in children with SCD. The literature has indicated that these strategies improved the knowledge that the children and their caregivers had about the disease, which consequently led to improvement in symptoms management at home andimpacted the re-admissions status. Some studies revealed that the re-admission rate was significantly reduced after the intervention. Overall, the findings from all of the studies suggested that both interventions (educational and CBT) improved different aspects of health outcomes (physical, psychosocial, and cognitive). However, those studies had several methodological limitations that limit the ability to draw a confirmative conclusion about the obtained findings. Two studies that utilized the educational intervention reported on improved coping skills (Shahine *et al*., 2015) and treatment adherence (Fre-Jones, 2009) post-intervention without indicating this in the study's aim. Moreover, coping usually occurs as a result of behavioral change after a period of time and it is not clear how the introduction of educational sessions for a few days impacted the long-term change in behavior or affected the coping skills of children with SCD for a period lastingless than two months. In addition, CBT works on an individual's thoughts, emotions, feelings, and actions. Therefore, it was expected that the studies that utilized CBT would report on the impact that the disease had on negative thoughts, feelings, and emotions in the pre-test. Instead, the majority of those CBT studies reported on the pain frequency and intensity, admission rate, and perceived coping ability in the pre-test data. In addition, some studies failed to reporton the cognitive dimension despite the fact that this is a core component of CBT therapy (see Table 2). Furthermore, all of the studies aimed to evaluate the intervention that was done on SCD children; however, four studies (Frei-Jones *et al*., 2009; Regan *et al*., 2011;Mahat *et al*., 2007; Hines *et al*., 2011) did not have baseline data to compare the results before and after the intervention and confirm that the intervention was effective. The limitation with a pre- and post-test design is the recall bias by the participants, which could have influenced the results. Moreover, utilizing such a design suggests the need for randomization. From 16 articles, only the studies conducted by Gill *et al*. (2001), Kaslow *et al*. (2012), and Thomas *et al*. (1999) established randomization; however, the study by Thomas *et al*. (1999) only described the method of randomization. The other three studies provided no information. The remaining studies recruited a convenience sample, which limits the representativeness of the population. In addition, the power calculation for the sample was only described by Frei-Jones (2009), and all of the studies recruited the sample from one setting. This indicates that the sample size may be too low; therefore, generalizability may not be possible. Moreover, most of the studies utilized questionnaires to measure the outcomes; however, four studies (Hazzard *et al*., 2002; Hines *et al*., 2011; Kaslow *et al*., 2012; Shahine *et al*., 2015) only reported the reliability of some of the tools that were used; while most of those studies did not indicate the reliability of the tool that was used. This makes it difficult to judge the validity of the obtained results and it may suggest that the findings may not be accurate. The studiesconducted byBarakat *et al*. (2010) and Hazzard *et al*. (2002) were the only ones that obtained different outcomes than the other studies in the psychological domain for the pre-test intervention and the post-test intervention. The inconsistencies in the findings from these studies could be linked to the tool used, as the reliability of the tools was only found to be adequate. Therefore, those tools may have failed to assess specific health aspects in contrast to the tools used in other studies. On the other hand, some studies (Dines *et al*., 1997; Gill *et al*., 1997; Gill *et al*., 2001; Hicks *et al*., 2006; McClellan *et al*., 2009) collected data using a non-standardized tool (diary analysis) and the data were subjectively analyzed by the researcher. This raises a question about using such a tool. Can it be considered 'valid' and sufficient to generate quality data? Therefore, utilization of this subjective tool may indicate an intrusion of personal bias into the analysis and the obtained results may not be accurate.

In addition, the study by Thomas *et al*. (1999) utilized an adult version of the questionnaires for children. It is anticipated that the children's experiences of pain, coping, and level of confidence to control pain are different than the experiences of adults. Therefore, utilizing the adult tool to measure the variables for children might indicate that the tool could be invalid and, therefore, the results may not be accurate. In addition, Shahine *et al*. (2015) utilized a translated tool without piloting it. It is well known that when a tool gets translated it may affect the tool's internal reliability, which might affect the study results. Furthermore, the statistical portion ofall of the reviewed studies was not satisfying. None of the studies had a clear description or rationale for using the selected statistical tests. None of the reviewed studies provided clear objectives and hypotheses to judge the tests. This is deemed important for understanding the use of statistics presented in those studies; for example, Dines *et al*. (1997) mentioned 'Friedman analysis' without identifying what this test was used for, and in the Fre-Jones *et al*. (2009) study the authors concluded that treatment adherence was improved without stating the method of measurement for that variable and how it was analyzed. In addition, all of the studies failed to provide information about the data distribution, skewness, test assumptions, or any other problems found in the data and the actions that were taken to correct these before running the presented statistics. This information could help judge the appropriateness of the tests used in these studies in order to trust the findings. Some studies (Gill *et al*., 2001; Regan *et al*., 20011; Shahine *et al*., 2015) tested the best predicated variables for the outcomes using linear regression, logistic regression, and general linear models; however, the model fitness was not explained and the adjusted R square, the F- test, and the sum of errors versus the variability percentages in the model were not explained. This makes it difficult to judge whether or not the reported variables are good predictors; without presenting clear data in the analysis section it is difficult to trustthe results. In addition, the duration of the interventions in all of the studies was low (in some studies it was only 3-5 days) and this makes it difficult to judge the effectiveness of the intervention in a very short period. If a longer intervention period had been assigned, a different result could have been yielded. In order to introduce a behavioral change, a long timeframe is required as it is only possible to observe the desired change in the participants if the time period of the intervention is sufficiently long.

Despite the limitations of these studies, they are still informative. The existing literature provided insights into the different types of interventions used to improve various aspects of HRQOL. An examination of the literature revealed that the studies that utilized technology for the educational interventions reported more desired health outcomes than the traditional interventions, such as educational teaching sessions and the teaching guide. Moreover, the use of wireless technology to deliver information in the educational sessions

not only improved the participants' knowledge about the disease and symptoms management, it also improved the social aspect of health. The studies that utilized technology reported that children improved their social interactions with peers and also their interactions with health care providers, which consequently improved their coping skills. As noted in the studies, when the duration of the intervention increased the coping skills and the social interaction skills of the children with SCD improved. The studies that assessed the impact of the interventionson children and their families reported better health outcomes than the studies thatonly assessed the impact of the intervention on one population. This indicates that the family plays an important role in the process of care and must be considered when implementing any intervention. Furthermore, educational intervention was found to be more applicable to the parents of SCD children and CBT seemed to be an appropriate intervention for the children. It seems that the social outcome was difficult to achieve utilizing the traditional method for teaching; in contrast, the technology method led to improving the social aspect of the quality of life for children with SCD. This is may be because, through technology,the children were easily connected to one another and this also provided them with an opportunity to connect with health care providers, which in turn improved the children'ssocialization. Generally, the literature proved that educational and CBT interventions help improve various aspects of health (physical, emotional, social, and cognitive); therefore, it could besummarized that utilizing technology and designing an educational intervention that consists of some training or guidelines along with disease information could potentially be a powerful strategy for improving health related quality of life for children with SCD. It appears that using technologyto educate children with SCD canclose the gap that could not be filled with other types of educational strategies, and doing so enables children with SCD to connect all of the aspects associated with health related quality of life.

Conclusion

The aim of this review was to identify strategies that help improve the HRQOL of children with SCD. Sixteen articles were reviewed and the findings suggested that two important strategies can help improve the HRQOL of this group: educational interventions and CBT interventions. This review found thateducational and CBT interventions were helpful in improving the participants'knowledge about the disease and increasing their ability to manage their disease symptoms, thus improving the physical, mental and cognitive aspects of health. In addition, the studies that incorporated innovative technology to deliver the intervention reported an improvement in the social aspect of health that was not reported in the studies that used the traditional route of delivery for the intervention. Therefore, designing an educational intervention approach with the aid of technology can be a powerful strategy that will close the health care practice gap and bring together all aspects of HRQOL. The literature also shed light on the importance of families as a key element that must be considered when designing any intervention. More research is required to examine the predictors of poor HRQOL in children with SCD via the use of longitudinal designs so that appropriate interventions can be designed. In addition, research is needed to assess the coping skills of theparents of children chronic with illness. Furthermore, it is important to create family-based interventions to improve the quality of life for children with SCD. Finally, future research is needed to design strategies that combine educational sessions and behavioral training in order to improve HRQOL for children with SCD.

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