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Review Article

Interventions to improve independence in basic and instrumental activities of daily living in individuals with myelomeningocele: an integrative literature review

Intervenções para melhorar a independência nas atividades básicas e instrumentais de vida diária em indivíduos com mielomeningocele: uma revisão integrativa da literatura

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Resumo

Objetivo: Esta pesquisa buscou revisar as evidências atuais sobre intervenções de terapia ocupacional para promover independência nas atividades de vida diária e atividades instrumentais de vida diária em indivíduos com Mielomeningocele. **Método:** Foram seguidos os critérios do PRISMA e pesquisadas as bases de dados PubMed, Web of Science, Cochrane Library, Embase, Lilacs, Scielo, PEDro e OTseeker, utilizando-se os descritores disrafismo espinhal, espinha bífida, mielomeningocele associados à reabilitação, independência, atividades de vida diária e terapia ocupacional. **Resultados:** Dos 523 artigos encontrados, 19 preencheram os critérios de inclusão/exclusão. Destes, 18 foram intervenções e um de revisão, resultando na seleção de 18 estudos. A análise quantitativa e descritiva revelou que o maior número de estudos publicados foi de intervenção baseada em acampamento, orientação cognitiva CO-OP para o desempenho ocupacional diário, programa de educação integrativa em dois passos e sistema móvel de saúde e reabilitação. As intervenções baseadas em acampamento, CO-OP e terapia baseada em ocupação mostraram maior independência dos participantes. **Conclusão:** Esta revisão apresentou uma síntese das intervenções que visam melhorar a independência nas AVDs e AIVDs em pessoas com MMC, seus referenciais teóricos e elementos comuns que favorecem a efetividade.

Palavras-chave: Espinha Bífida, Atividade de Vida Diária, Área de Dependência-Independência, Terapia Ocupacional, Reabilitação.

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Abstract:

Objective: This research reviews current evidence on occupational therapy interventions for promoting independence in activities of daily living and instrumental activities of daily living in individuals with Myelomeningocele. **Method:** The PRISMA criteria were adopted and, PubMed, Web of Science, Cochrane Library, Embase, Lilacs, Scielo, PEDro and OTseeker were searched, using the descriptors spinal dysraphism, spina bifida and myelomeningocele associated with rehabilitation, independence, activities of daily living and occupational therapy. **Results:** Of the 523 articles found, 19 met the inclusion/exclusion criteria. Of these, 18 were interventions and one a review, resulting in the selection of 18 studies. A quantitative and descriptive analysis revealed that the highest number of published studies were camp-based intervention, Cognitive Orientation to Daily Occupational Performance and Two-Step Integrative Education Program and Mobile Health and Rehabilitation system. The camp-based interventions, CO-OP and occupation-based therapy showed increased independence of the participants. **Conclusion:** This review presented a synthesis of interventions aimed at improving independence in ADLs and IADLs in people with MMC, their theoretical frameworks and common elements that favor effectiveness.

Keywords: Spina Dysraphism, Activity of Daily Living, Field Dependence-Independence, Occupational Therapy, Rehabilitation.

Introduction

Myelomeningocele (MMC), the most common form of spina bifida (SB), is a congenital neural tube defect in which the bones of the spine do not completely form during the fourth week of pregnancy, leading to herniation of the meninges and spinal cord (Sahni et al., 2021). Between 2017 and 2019, the prevalence of spina bifida in Brazil was 2.67 for every 10,000 births (Orioli et al., 2020). People with MMC have different degrees of neurological impairment depending on the level of the injury, generally exhibiting complete paralysis and loss of sensitivity below the injury, as well as altered bladder and intestinal function (Ulsenheimer et al., 2004). The condition is typically associated with hydrocephaly and Chiari-II malformation (Sahni et al., 2021).

Advances in medical care and rehabilitation in recent years have resulted in increased life expectancy in people with MMC, with most reaching adulthood (Davis et al., 2005). However, these individuals have difficulty achieving independence and autonomy in activities of daily living (ADLs), such as bathing, dressing, independence from toileting, and instrumental activities of daily living (IADLs), such as cooking and managing finances, particularly in individuals with hydrocephaly and spinal cord injury above L2 (Davis et al., 2006; Luz et al., 2017; Steinhart et al., 2021).

In the literature, authors use different terms to refer to daily activities. The present study uses the definitions proposed by the American Occupational Therapy Association in the Occupational Therapy Practice Framework (American Occupational Therapy

Association, 2020), which defines ADLs as "activities involving self-care", including bathing, toileting and personal hygiene, dressing, eating/swallowing, functional mobility, personal care and sexual activity, and IADLs as "activities that support daily life at home and in the community", such as caring for others, caring for pets, educating children, managing communication, driving and mobility in the community, managing finances and the home, preparing meals, religious and spiritual expression, safety procedures, emergency responses and shopping (American Occupational Therapy Association, 2020).

Different interventions have been proposed to increase independence in ADLs for people with MMC, including camp-based experiences (Bodzioch et al., 1986; Bolding & Llorens, 1991; Driscoll et al., 2019; Holbein et al., 2013; O'Mahar et al., 2010; Zimmerman et al., 2019), increasing participation opportunities (Harr et al., 2011), Cognitive Orientation to Daily Occupational Performance (CO-OP) (Öhrvall et al., 2020; Peny-Dahlstrand et al., 2009; Steinhart et al., 2021), assistive technology (Dicianno et al., 2016a; Jennings et al., 2020), targeted interventions to improve self-catheterization independence (Clarkson, 1982; Donlau et al., 2013; Hannigan, 1979; Neef et al., 1989), and wheelchair skills training (Liptak et al., 1992; Sawatzky et al., 2012). However, there are still no review studies that summarize this knowledge. For this reason, the present study aimed to identify and analyze scientific evidence on interventions used to increase independence in ADLs and IADLs in this population.

Materials and Methods

This is a literature review, which involves synthesizing knowledge and incorporating the practical applicability of the results of significant studies (Souza et al., 2010). This method was selected because of its broader approach, allowing the inclusion of experimental and nonexperimental studies to fully understand the phenomenon studied (Souza et al., 2010).

According to Souza et al. (2010), an integrative review consists of the following stages: defining the clinical problem, identifying the necessary information, data collection and a critical appraisal of evidence, establishing the applicability of the data obtained from the publications, and determining their usefulness to the patient. The research aimed to identify which interdisciplinary or occupational therapy interventions for individuals with MMC include independence in ADLs and IADLs as one of the evaluated outcomes.

Rigour

The researcher followed the criteria adopted by PRISMA devised and a data collection process aimed at synthesizing the information gathered in the review. Bibliographic and methodological data were extracted for each study, including names of the authors, year of publication, sample size, participants' ages and diagnosis, description of the intervention, measurement tools and intervention results. The level of evidence of each study was classified in accordance with Stillwell et al. (2010), based on the study design: Level I (systematic reviews and meta-analyses), Level II

(randomized clinical trials), Level III (nonrandomized clinical trials), Level IV (cohort and case-control studies), Level V (descriptive studies and systematic reviews of qualitative research), Level VI (qualitative or descriptive studies), Level VII (expert opinion).

Databases and search strategy

The PubMed, Web of Science, Cochrane Library, Embase, Lilacs, Scielo, PEDro and OTseeker databases were searched for studies published between January 1, 2010 and March 1, 2021. The search strategy used the descriptors spinal dysraphism, spina bifida and myelomeningocele associated with the descriptors rehabilitation, independence, activities of daily living and occupational therapy, in English or Portuguese. The following combinations were used: ("Spinal Dysraphism" OR Meningomyelocele OR myelomeningocele OR "spina bifida") AND (Rehabilitation OR Independence OR "Activities of Daily Living" OR "Occupational Therapy").

Inclusion criteria were: (a) studies involving interdisciplinary rehabilitation or occupational therapy interventions for people diagnosed with spina bifida or myelomeningocele (b) with independence in ADLs or IADLs as one of the outcomes assessed.

The exclusion criteria were: (a) those involving surgical interventions, medication-based therapy or specific or restrictive procedures from other rehabilitation professions (b) investigations with mixed populations that did not describe the specific results of individuals with MMC, (c) clinical opinion articles, commentaries, or conference proceedings, and d) articles that did not have open access.

Data analysis

A quantitative analysis of the data was performed, where the authors grouped the number of articles according to the following categories: description, theoretical framework of the intervention and level of evidence, type of interventions, assessments used, and results obtained. Subsequently, a descriptive analysis was performed, highlighting the following categories: description of the interventions, assessments used, and results obtained and the intervention elements that favor effectiveness in improving independence in ADLs and IADLs among individuals with MMC.

The search identified a total of 926 articles (Pubmed – 229, Cochrane – 46, Web Science – 288, Embase – 351, Lilacs – 5, Scielo – 2, OTseeker – 3, PEDro – 2), 403 of which were excluded as duplicates. The titles and abstracts of 523 articles were read and a total of 62 were selected for full-text screening, independently performed by the two authors.

Eighteen articles met the inclusion criteria of this review. Figure 1 shows the flowchart of the literature review process.

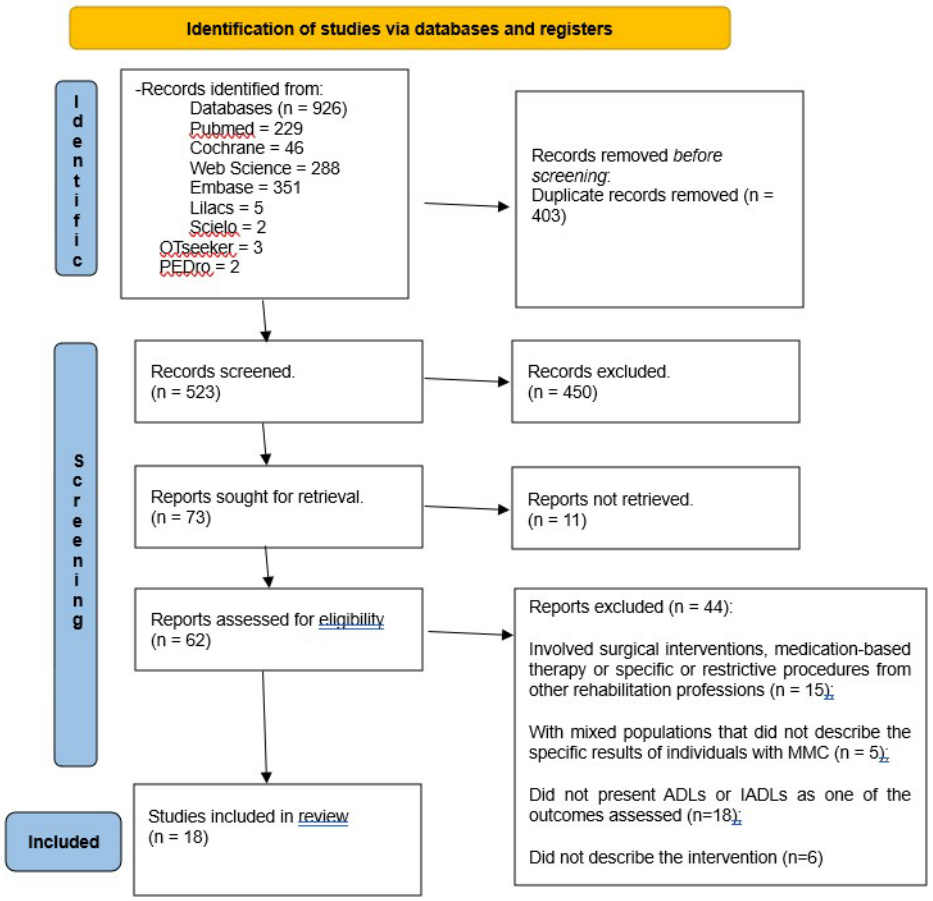

Figure 1. Flowchart of the literature review process. *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). **If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools. *From:* Page et al. (2021).

Results

Table 1 presents the characterization of the articles by lead author, year of publication, study objective, sample description, theoretical framework of the intervention and level of evidence.

Table 1. List of the articles by lead author, year of publication, study objective, sample description, theoretical framework of the intervention and level of evidence.

Lead author and Year	Objective	Sample	Theoretical framework	Level of Evidence
O'Mahar et al. (2010)	Assess a camp-based intervention aimed at independence in children, adolescents and adults with SB.	- **Size:** Initial: 76 Final: 74 - **Diagnosis:** 98% MMC - **Age:** M = 16.61 years (SD = 6.07); variation: 8–37 - **Sex:** 43% males	Not described	III

Table 1. Continued…

Lead author and Year	Objective	Sample	Theoretical framework	Level of Evidence
Harr et al. (2011)	Explore the influence of household task participation on home, community, and work opportunities for a youth with multiple disabilities.	- **Size:** 1 - **Diagnosis:** MMC - **Age:** 20 years - **Sex:** male	Self-determination theory and occupation-based therapy	IV
Sawatzky et al. (2012)	Assess the effectiveness of a wheelchair skills training program (WSTP) and its effect on participation in domestic and community settings.	- Size: 6 - Diagnosis: SB=5, SCI=1 - Age: M= 12.3 SD: 4.5 -Sex: 2 males / 4 females	Not described	III
Holbein et al. (2013)	1) Examine the effectiveness of a camp-based intervention modified from O'Mahar et al. (2010). 2) Identifying the conditions and characteristics of participants that moderated intervention effectiveness.	- Size: Initial: 119 Final: 73 - Diagnosis: 83.2% MMC - Age: M = 16.16 years (SD = 6.50); variation: 7-41 - Sex: 49 males / 70 females	Not described	III
Donlau et al. (2013)	Assess the effects of a step-by-step mutual goal setting program together with documentation and feedback on training self-care in toilet activities.	- **Size:** 22 - **Diagnosis:** MMC - **Age:** M = 9.1 years (SD = 5.5); - **Sex:** 12 girls and 10 boys	Not described	III
Khan et al. (2015)	Evaluate the effectiveness of an interdisciplinary outpatient rehabilitation program for people with SB in a cohort of the Australian community.	- **Size:** Initial: 54 Final: 50 – Intervention Group (IG) N=26 Control Group (CG)) N=24 – **Diagnosis:** SB **Average age** IG: 32.9 / CG: 29.7	Not described	II
Dicianno et al. (2017)	Determine whether an evidence-based wellness program for individuals with SB and SCIs would improve the health results and care experience of a patient and provide a positive return on investment.	- Size: Initial: 65 Final: 52 - Diagnosis: 35 MMC / 17 SCI - Average age: 38.7 ± 14.1	Multidisciplinary care	III
Dicianno et al. (2016a)	Determine the viability of using an interactive Mobile Health and Rehabilitation system (iMHere) on SB and its effect on psychosocial and medical outcomes.	- Size: 23 CG: 10 Participants / IG: 13 participants. - Diagnosis of MMC. - Average age of 29 years	Not described	II
Dicianno et al. (2017)	1. Qualitatively analyze the goals set by patients with SB and SCIs in a wellness program to generate a list of software requirements for a goal setting module in iMHere. 2. Design a basic goal setting module in iMHere, based on the Patient-Specific Functional Scale (PSFS). 3. Identify the educational needs of our target population to establish important content for the iMHere educational module.	- Size: Initial N = 65, Final N = 50 - Diagnosis = 37 (74%) SB; 13 (26%) SCI. - Sex = 24 (48%) women; 26 (52%) men - Age: M= 38.7 (SD 14.1) years.	Self-determination theory	III

Table 1. Continued…

Lead author and Year	Objective	Sample	Theoretical framework	Level of Evidence
Rice et al. (2017)	Describe a transfer training intervention and examine its feasibility in improving participants' skills in the short term.	- Size: 12 - Diagnosis: 41.7% with SB - Average age =15.69 (SD ± 1.44) years, varying between 13 and 18 years.	Not described	II
Kokkoni et al. (2018)	Assess the feasibility of configuring and using an in-home body weight support system (BWSS) by a child with spina bifida, and quantify changes in locomotor activity and walking performance when off the BWSS.	- **Size:** 1 - **Diagnosis:** MMC - **Age:** 5 years - **Sex:** boy	Not described	IV
Choi et al. (2019)	Develop and test the feasibility of a two-stage self-management program, including integrative education and a mobile health program for children with SB.	- Size: 5 - Diagnosis = SB - Age between 11 and 12 years	Individual and family self-management theory (IFSMT)	III
Driscoll et al. (2019)	Examine associations between camp-based psychosocial intervention dosage and changes in independence in young people with SB	- Size: 110 - Diagnosis: MMC 87% - Average age = 14 years 7 months, SD = 6 years 1 month, ranging between 6 and 32 years - Sex: 66 girls, 54 boys	Not described	III
Zimmerman et al. (2019)	Outline the development and evolution of Camp V.I.P., describe the participants; and provide quantitative and qualitative feedback from participants	- Size: 63 - Diagnosis: SB - Age: 6 to 17 years, with a median age of 11 years - Sex: 59% girls	Not described	III
Peny-Dahlstrand et al. (2009)	Investigate whether the CO-OP approach is feasible and potentially beneficial to adolescents and young adults with CP or SB, analyzing four areas of feasibility (acceptability, efficacy, adaptation and expansion).	- Size: Initial N = 13, Final N = 10 - Age: 16 - 28 years - Diagnosis: 5 with SB (2 women and 3 men) and 5 with CP (2 women and 3 men)		III
Steinhart et al. (2021)	Investigate the effect of the CO-OP approach using telerehabilitation on improving task performance, functional dependence and quality of life in adolescent with MMC, and determine whether any change in outcome was maintained long term.	- Size = 4 - Age: 14 to 18 years - Diagnosis: MMC - Sex: 3 boys and 1 girl		III
Jennings et al. (2020)	Determine whether the Octopus watch is a feasible intervention to promote purposeful ADLs in a group of children with SB; investigate the potential of the watch to increase physical activity; compensate for impaired executive functioning; the effect of the intervention on ADLs and acceptance of the octopus watch technology.	- Size = 4 - Diagnosis = SB - Age: 3.5-7 years - Sex: 2 girls and 2 boys	Not described	III

Table 1. Continued…

Lead author and Year	Objective	Sample	Theoretical framework	Level of Evidence
Choi et al. (2020)	Investigate the effects of a two-stage self-management improvement program, including an on-site integrative education program and mobile health for children with SB	- Size = 36 - Diagnosis = SB - Age = 7 to 12 years	Individual and family self-management theory (IFSMT)	III

MMC = myelomeningocele; M = mean; SB = spina bifida; SCI = spinal cord injury; SD = standard deviation.

Of the studies analyzed, 3 were randomized controlled trials (Dicianno et al., 2016a; Khan et al., 2015; Rice et al., 2017), 13 quasi-experimental with only an intervention group and pre- and post-treatment assessment (Choi et al., 2019, 2020; Dicianno et al., 2016b, 2017; Donlau et al., 2013; Driscoll et al., 2019; Holbein et al., 2013; Jennings et al., 2020; O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009; Sawatzky et al., 2012; Steinhart et al., 2021; Zimmerman et al., 2019) and 2 case reports (Harr et al., 2011; Kokkoni et al., 2018). Nine studies analyzed adult participants (older than 18 years) (Dicianno et al., 2016a, 2016b, 2017; Driscoll et al., 2019; Harr et al., 2011; Holbein et al., 2013; Khan et al., 2015; O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009).

Only 5 articles cited the theories that provided the theoretical foundation that underpins the approach to intervention, with 4 models identified: self-determination theory (Dicianno et al., 2017; Harr et al., 2011); patient-centered care and occupation-based interventions (Harr et al., 2011), individual and family self-management theory (Choi et al., 2019; 2020) and multidisciplinary care (Dicianno et al., 2016b).

The table below presents a description of the interventions, the assessments used and results obtained.

Table 2. Description of the interventions, assessments used and results obtained.

Author and Year	Intervention	Assessments Performed	Results
O'Mahar et al. (2010)	**Duration:** One week, at night.	- Goal Attainment Scale.	Improvements in individual SB-related and social goals and gains in management of SB-related responsibilities and general tasks
	Stage 1: collaborative identification of self-care and social goals; 2: daily group sessions involving psychoeducation and cognitive strategies 3: counselor monitoring of camper goals to:	- Sharing of Spina Bifida Management Responsibilities (SOSBMR).	
	(a) review goals, (b) review steps to achieve goals, (c) discuss barriers (d) discuss how the goals can be achieved.	- Spina Bifida Independence Survey (SBIS).	
		- Knowledge of Spina Bifida measure (KOSB)	
Harr et al. (2011)	**Duration:** 8 weeks.	- Arc's Self-Determination Scale (SDS), Adolescent Version	CHORES: Overall performance improved in 17 pre-test and 19 post-test tasks, but declined for 16 tasks at follow-up.
	- Setting intervention goals; - Instructions on language and behavior: praise, rewards, environmental structure, repetitive verbal, visual and physical cues. – Position and environmental adjustments. – Compiling a checklist – Reward system. – In-person and telephone-based monitoring	- Children Helping Out: Responsibilities, Expectations, and Supports (CHORES)	SDS: increased from the 57th to 78th percentile at follow-up.
		- Canadian Occupational Performance Measure (COPM)	COPM: performance and satisfaction scores for washing the dishes improved from pre- to post-test and from post-test to follow-up.

Table 2. Continued…

Author and Year	Intervention	Assessments Performed	Results
Sawatzky et al. (2012)	**Duration:** 9 hours on two consecutive Saturdays.	- Wheelchair Skills Test (WST)	Wheelchair skills improved (WST increased from 66 to 75)
	Skills were taught via verbal explanations and demonstrations, breaking down the components of each skill. One 1-hour wheelchair maintenance session conducted by parents.	- Activity Scale for Kids (ASK)	- Questionnaire: revealed three themes: (I) developing independence; (II) improving wheelchair skills; and (III) reducing shoulder pain.
		- Impact questionnaire	Community participation declined, but was not statistically significant.
Holbein et al. (2013)	**Duration:** one week, at night.	- Goal Attainment	Gains in health goals; responsibility for tasks involving communication, walking, general self-care, skin care, catheterization and intestinal programs. None of the statistically significant findings were clinically significant.
	Three main components: (1) establishing goals, (2) counselor monitoring of these goals, and (3) daily 1-hour-long workshops.	- Social Skills Measure	
		- Social Acceptance subscale from Harter's Self Perception Profile	
		- Sharing of Spina Bifida Management Responsibilities (SOSBMR).	
		- Spina Bifida Independence Survey (SBIS).	
Donlau et al. (2013)	**Duration:** 2 home visits were conducted with 16 families, 3 with 6 families, with a median 40-day interval (average = 60 days, range = 20-191) between the first and last visit.	- Structured observation manual.	- Increased independence in the CIC and TRI groups
	Home visit by a urotherapist and occupational therapist and to observe toileting performance. Environmental adjustments as needed. Setting individual goals. A spreadsheet was given to each child to record performance in hygiene-related tasks. Tasks performed independently by the child were written in black, those that required support in red, and training tasks in green.	- Goal Attainment Scale (GAS)	- Individual goals: All the children improved and 17 achieved their individual goal or did more than expected.
		- Canadian Occupational Performance Measure (COPM)	- The performance scores of the children (n = 16) in the COPM showed a significant negative difference between the first and last home visit (m= 5.6 at the outset, m =3.5 after training; p = 0.008)
Khan et al. (2015)	**Duration:** 30-minute individual therapy sessions, 2-3 times a week for 6 weeks	- Guy's Neurological Disability Scale (NDS)	the intervention group improved significantly at the 3-month follow-up for the primary and secondary outcomes, with moderate- to -large effect sizes (r): urinary / intestinal dysfunction (AUA, UDI6, IIQ7, WFIS); and cognitive function: NDS "cognitive" and "mood"; DASS "depression", "anxiety" and "stress", "psychological symptoms"; "active coping" and "self-efficacy" scores
	Physical reconditioning program, wheelchair assessment skill reacquisition tasks and adaptive techniques for the whole body. Participants subsequently took part in similar maintenance programs at home or in the community. In addition to the outpatient rehabilitation program, participants in the treatment group received individualized care focused on self-care, continence and skin care education, and cognitive-behavioral program for more than 4-6 weeks.	- Urogenital Distress Inventory (UDI6)	
		- American Urological Association Symptom Index (AUA)	
		- Incontinence Impact Questionnaire (IIQ7)	
		- Wexner Faecal Incontinence Score (WFIS)	
		- Depression Anxiety Stress Scale (DASS)	
		- McGill Quality of Life Questionnaire (MQOL)	
		- Brief COPE scale (B-COPE)	
		- Generalized Self-Efficacy Scale (GSE)	

Table 2. Continued…

Author and Year	Intervention	Assessments Performed	Results
Dicianno et al. (2016a)	**Duration:** 2 years	Health outcomes:	All the health and care outcomes improved significantly at the end of the 2-year period.
	4 main components:	Function: Craig Handicap Assessment and Reporting Technique-Short Form (CHART-SF)	There was a significant decline in emergency room visits between baseline and year 2.
	Evidence-based guidelines on preventing and treating pressure sores; neurogenic depression, bladder and bowel control; nutrition and physical activity.	Mood: Beck Depression Inventory-II (BDI-II)	Costs associated with avoidable diseases did not differ significantly from those at the onset of the study.
	Case management: The wellness plan consisted of 5 short-term, 5 long-term and 5 maintenance goals. Quarterly assessment meetings were conducted for 2 years, with access to unlimited telephone support and the possibility of scheduling additional visits.	Quality of life: World Health Organization Quality of Life-Brief Form (WHOQOL-BREF)	
	Patient education: 10 modules that cover issues specific to individuals with SB and SCIs.	Self-rated health: questionnaire	
	Incentives: participants were eligible to receive up to 4 US $ 25 gift vouchers each for progress towards their wellness goals.	Care outcomes:	
		Perception of patient-centered care: The Patient Assessment of Chronic Illness Care (PACIC)	
		Knowledge of avoidable conditions: multiple choice questionnaire	
		Utilization and cost outcomes	
		Total medical and pharmaceutical costs.	
Dicianno et al. (2016b)	**Duration:** 1 year	- Patient Assessment of Chronic Illness Care (PACIC). - WHOQOL-BREF. - Number of urinary tract infections (UTIs), skin lesions, emergency room visits due to UTIs or skin lesions, planned and unplanned hospitalization.	Significant improvement in physical independence. There was a trend towards a decline in medical events for the intervention group. Significant improvement in self-management skills for the intervention group with considerable use of the system.
	iMHere is a set of 6 modules (medication, bladder and intestinal management, skin care, depressive symptoms, exchanging messages) for Android smartphones.		
Dicianno et al. (2017)	**Duration:** 2 years	Evaluation and thematic classification of participants' goals	Fifteen themes were identified in the 750 wellness goals.
	Evidence-based guidelines and case management provided full-time by a nurse and case management as described by Brad E. Dicianno et al. (2016b).		Of the 750 wellness goals, 669 (89%) were achieved and 81 (11%) were not. Male participants with SCI were more likely to achieve their goals than females or those with SB. Short-term goals were more likely to be achieved.
Rice et al. (2017)	**Duration:** 1 day	- Transfer Assessment Instrument (TAI)	The intervention group obtained significantly higher scores. There were no significant differences in social competence and self-perception.
	Participants watched a 9-minute video describing important transfer-related components, including adequate arm positions, body positioning, conservation techniques, movement strategies and hand placement. The video breaks transfers down into three phases: set up, flight and landing. The recently learned skills were practiced via performance feedback.	- Self-Perception Profile for Children (SPPC)	

Table 2. Continued…

Author and Year	Intervention	Assessments Performed	Results
Kokkoni et al. (2018)	**Duration:** equipment available at home 24 hours a day, 7 days a week for 10 weeks.	Feasibility: team observation	Locomotor activity and involvement in sports during BWSS use increased at the end of the intervention.
	(1) body weight support system, (2) simultaneous use of all the extremities and (3) involvement in sports activities.	Affection: reported by parents on a 10-point scale	Post-study PEDI and GMFM were very high across all domains, with the greatest improvements in posture and walking.
	The technology was a semi-permanent BWSS constructed and installed by an engineering company (Enliten, LLC, Newark, Delaware). The 2 main features were the suspended support rails and counterweight system.	Locomotor activity: number of steps and falls counted via weekly videos	
		Involvement in sports: type and duration of any sports activity counted via weekly videos	
		Mobility: GMFM	
		Gait: 6-minute walk test	
Choi et al. (2019)	**Duration:** 4-and-a-half-hour course over 6 sessions.	School adjustment	There was no difference in the five measures pre-test or the first or second measure post-test, except for the self-management behavior domain. Children with SB expressed their satisfaction in meeting other children with the same condition.
	Different teaching methods (including a lecture and discussion), laboratory exercise (using a human anatomy model), as well as dramatization and group activities (using a board game addressing aspects of family life, school, friendship and the participants themselves).	Knowledge of self-management	
	Based on the content of the integrative education program, an Android application called "Glowing Stars ™" was designed, selecting the indicators: self-monitoring of urination, defecation, skin care, taking medication, and mood.	Self-efficacy	
		Self-management: Kennedy Krieger Independence Scale-Spina Bifida Version (KKIS-S)	
		Quality of life: Health-related quality of life (HRQOL)	
Driscoll et al. (2019)	Similar intervention to that	- Sharing of Spina Bifida Management Responsibilities (SOSBMR)	An increase in intervention dosage was associated with greater camper independence in executing SB-related self-management tasks. The dosage was not associated with changes in social skills.
		- Spina Bifida Independence Survey (SBIS);	
		- Social Skills Measure	
		- Wechsler Abbreviated Scale of Intelligence;	
Zimmerman et al. (2019)	**Duration:** 3 days	Questionnaire to assess participants' growth in terms of confidence and independence and qualitative data for the open response sections.	Most of the parents reported increased independence and confidence in the children and the formation of friendships.
	1) an immersive experience 2) carefully constructed challenges, such as adaptable skiing, ensuring the individual will be able to overcome the challenge, and e 3) SB-related educational activities.		
Peny-Dahlstrand et al. (2009)	**Duration:** 11 sessions	- COPM;	Significant gains in performance and satisfaction in the COPM. OSA: no change. AMPS: no change. DEX: all the participants reported fewer executive function difficulties after intervention. Tower Test: 9 participants showed improved performance.
	Patient-centered approach that identifies the skills to be learned via a problem-solving process focusing on four global strategies – goal, plan, do, check.	- The Swedish	
		version of the Occupational Self-Assessment (OSA) tool;	
		- Assessment of Motor and Process Skills (AMPS);	
		- The Dysexecutive Questionnaire (DEX);	
		- Delis-Kaplan Tower Test	
		– Kaplan Executive Function System	

Table 2. Continued…

Author and Year	Intervention	Assessments Performed	Results
Steinhart et al. (2021)	**Duration:** 10-12 sessions lasting 30-60 minutes.	Canadian Occupational Performance Measure (COPM)	There were clinically significant improvements in performance and satisfaction post-intervention and at follow-up for trained and untrained goals.
	Meeting with an occupational therapist trained in CO-OP via a teleconferencing application (Skype TM).	Wee Functional Independence Measure (Wee-FIM)	All the participants showed clinically significant improvements (greater than 4.5%) in their functional status according to the total Wee-FIM score. The change in PEDSQL 4.0 scores was inconclusive. Manual coding of the interview responses revealed 3 main themes: Intervention results, therapeutic relationship, remote delivery.
	The main resources included (1) patient-centered goals chosen by the child; (2) use of global problem-solving strategies, "Goal Plan Do Check" and domain-specific strategies (3) session format (4) dynamic performance assessment; (5) enabling principles, designed to support the acquisition, generalization and transfer of skills; (6) guided discovery facilitated by the therapist; and (7) involvement of parents or another important person.	PedsQL 4.0 Measurement Model for the Pediatric Quality of Life Inventory	
		Feedback interview	
		Field notes	
Jennings et al. (2020)	**Duration**: 16 days.	Childhood executive functioning inventory (CHEXI), Semi-structured interview, Canadian occupational performance measure (COPM).	Participants exhibited an average increase in physical activity of 36%. Executive function showed minimal change in working memory and more promising decline in inhibition. Average performance and satisfaction scores on the COPM rose from pre to post-test from 2.1 to 2.4. Three main themes emerged from the data: develop a routine, encourage independence and exhibit the watch.
	The Octopus watch developed by HeyJoy was designed for children, teaching them the concepts of time and routine, while encouraging them to remain active using an integrated fitness tracker. It links time to activities by visual icons. More than 2000 ADL icons are available in the smartphone application that accompanies it, including in the following areas: self-care, play timer, domestic tasks and meal time.		
Choi et al. (2020)	**Duration:** a half-day course (4.5 hours), six sessions. Experimental group 2 used the mHealth program daily for four weeks at home.	School adjustment: scale	This intervention program produced no significant difference in the quantitative results between the experimental and control groups, but qualitatively, the child participants and their parents responded positively to the program.
	The children of experimental group 1 only underwent the integrated education program (IEP), while their experimental group 2 received both the IEP and mHealth programs. Control group children received no intervention. The IEP involves several teaching methods, such as lectures and discussions, laboratory exercises, dramatizations and group activities. The 'Glowing Stars ™' application includes self-monitoring of urination, defecation, skin care, drug use and mood state.	Knowledge of self-management. Self-management knowledge scale	
		Self-efficacy: New General Self-Efficacy scale	
		Self-management behavior: Kennedy Krieger Independence Scale-Spina Bifida Version (KKIS-S)	
		Quality of life: Children's health-related quality of life (HRQoL)	

SB = spina bifida.

As shown in Table 2, the interventions identified varied considerably in terms of duration (1 day to 2 years). The assessments most used were the Canadian Occupational

Performance Measure (COPM), applied in 5 studies, and the Goal Attainment Scale, Sharing of Spina Bifida Management Responsibilities (SOSBMR) and Spina Bifida Independence Survey (SBIS), in 3 studies.

The interventions with the most available evidence were the camp-based, the Cognitive Orientation to Daily Occupational Performance (CO-OP), the Two-Step Integrative Education Program and Mobile Health and Rehabilitation system (iMHere).

Our review selected studies with interventions that had ADL or IADL as one of the assessed outcomes. Among the studies found, 8 had the gain of independence in ADL and/or IADL as the primary objective of the intervention and all presented positive outcomes in their results (Driscoll et al., 2019; Holbein et al., 2013; Jennings et al., 2020; O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009; Steinhart et al., 2021; Harr et al., 2011, Zimmerman et al., 2019). Four studies had as their primary objective the increase of independence in specific activities of daily living, such as general mobility (Kokkoni et al., 2018), wheelchair mobility (Sawatzky et al., 2012), transfers (Rice et al., 2017) and toileting (Donlau et al., 2013). The other articles presented interventions whose primary objective is associated with occupations classified by the American Occupational Therapy Association (2020) as health management, namely activities related to developing, managing and maintaining health and wellness routines, including self-management with the goal of improving or maintaining health to support participation in other occupations (Choi et al., 2019, 2020; Dicianno et al., 2016a, 2016b, 2017; Khan et al., 2015).

Table 3 lists the elements of the interventions that favor their effectiveness in people with MMC.

Table 3. Description of the studies by lead author and intervention elements that favor effectiveness.

Lead Author, Year	Intervention elements that favor effectiveness
Interventions with ADL as a primary objective	
O'Mahar et al. (2010)	- Setting individual goals;
	- Use of cognitive strategies to solve problems;
	- Dividing goals into stages;
	- Educational group
Holbein et al. (2013)	- Setting individual goals;
	- Use of cognitive strategies to solve problems;
	- Dividing goals into stages;
	- Educational group
Driscoll et al. (2019)	- Setting individual goals;
	- Use of cognitive strategies to solve problems;
	- Dividing goals into stages;
	- Educational group
Zimmerman et al. (2019)	- Family participation;
	- Educational group
Harr et al. (2011)	- Goal setting;
	- Guidance on adapting positions and the environment;
	- Family participation;
	- In-person and remote monitoring via telephone;
Peny-Dahlstrand et al. (2009)	- Setting individual goals;
	- Use of cognitive learning and problem-solving strategies;
	- Family participation;
Steinhart et al. (2021)	- Telerehabilitation format;
	- Setting individual goals;
	- Use of cognitive learning and problem-solving strategies;
	- Family participation;

Table 3. Continued…

Lead Author, Year	Intervention elements that favor effectiveness
Interventions with ADL as a primary objective	
Sawatzky et al. (2012)	- Breaking down the skill to be trained;
	- Family participation;
Donlau et al. (2013)	- Setting individual goals;
	- Training in the **natural settings**;
	- Breaking the task down into stages;
	- Family participation;
Rice et al. (2017)	- Use of an audiovisual resource (video of the correct technique)
	- Opportunity for task-specific training with feedback
Kokkoni et al. (2018)	- Training in the **natural settings**;
Jennings et al. (2020)	- Setting individual goals;
Intervention by health management	
Khan et al. (2015)	- Educational group
Dicianno et al. (2016a)	- Setting individual goals;
	- Educational group
Dicianno et al. (2016b)	- Use of an application to manage specific SB-related issues
Dicianno et al. (2017)	- Setting individual goals;
	- Educational group
Choi et al. (2019)	- Use of an application to manage specific SB-related issues
	- Educational group
Choi et al. (2020)	- Use of an application to manage specific SB-related issues
	- Educational group

As shown in Table 3, there are several common elements in the different interventions that seem to contribute to their effectiveness in improving independence in ADLs and IADLs among individuals with MMC.

Setting individual goals for the intervention program was a common element in 10 studies (Dicianno et al., 2016a, 2017; Donlau et al., 2013; Driscoll et al., 2019; Harr et al., 2011; Holbein et al., 2013; O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009; Steinhart et al., 2021) and **participation by parents and family members** took place while defining the goals and objectives of interventions and during the proposed programs in 9 investigations (Donlau et al., 2013; Driscoll et al., 2019; Harr et al., 2011; Holbein et al., 2013; O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009; Zimmerman et al., 2019; Steinhart et al., 2021; Sawatzky et al., 2012), **Cognitive learning strategies** were used in camp-based and CO-OP interventions (Driscoll et al., 2019; Holbein et al., 2013; O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009; Steinhart et al., 2021) and **training the stages of an activity in natural settings** was described in a study to improve toileting independence (Donlau et al., 2013) and camp-based interventions (Driscoll et al., 2019; Holbein et al., 2013; O'Mahar et al., 2010). **Telerehabilitation** in the form of synchronous care was used in the CO-OP approach and in 3 studies that evaluated mobile interactive systems for smartphones to facilitate self-management of specific SB-related tasks, such as medication, bladder and intestinal management, skin care and depressive symptoms (Choi et al., 2019, 2020; Dicianno et al., 2016a). **Educational groups** that addressed topics such as bladder and intestinal management, skin care and lesion prevention, nutrition and mental health were intervention elements in 9 studies (Choi et al., 2019, 2020; Dicianno et al., 2016b, 2017; Driscoll et al., 2019; Holbein et al., 2013; Khan et al., 2015; O'Mahar et al., 2010; Zimmerman et al., 2019).

Discussion

This integrative review identified and analyzed 18 articles about the interventions considered effective at promoting independence in ADLs and IADLs for individuals with MMC. Few randomized controlled trials were found, which are considered the most suitable methodological design to determine the effectiveness of an intervention. In addition, the participant age and intervention duration and design varied, and few studies reported the theoretical framework of the intervention.

Nevertheless, critical analysis of the studies demonstrated that the occupation-based and patient-centred approaches were present in a range of interventions. These approaches involve active patient participation when negotiating objectives, with their needs and goals considered a priority and crucial to assessment, intervention, and the expected outcomes. The approach targets the patients' goals, needs, and desires, considering their abilities and the context of their environment (Pontes & Polatajko, 2016). Moreover, while there is no citation of the theoretical model utilized, some interventions such as CO-OP have their theoretical foundations described in the literature (Missiuna et al., 2001). These foundations encompass conceptual bases in learning and problem-solving theories, as well as the principles of motor learning and motor control, strategy use theories and child -centered interventions.

The results of the camp-based interventions, CO-OP and occupation-based therapy, whose primary objective was the improvement of performance in ADL, showed increased independence of the participants in relation to the individual goals established, as evaluated by the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scale (GAS). The camp-based intervention and CO-OP were the ones with the highest number of studies.

The camp-based intervention format was used in the largest number of studies. In research by Holbein et al. (2013) and O'Mahar et al. (2010), the authors observed significant changes in individual self-care goals and overall independence in SB-related tasks; and Driscoll et al. (2019) demonstrated that these results are enhanced with repeated participation in these camps. In a study by Zimmerman et al. (2019), 86% of caregivers reported that their child's independence improved after participating in the camp. The factors that contributed the most were camp activities (44%), bonding with the volunteer (20%) and acquiring new skills (20%).

The CO-OP approach was assessed in two studies, one using a virtual application format (Steinhart et al., 2021). The results of these studies indicate significant improvements in performance and satisfaction, with performance for individual goals measured by the COPM after intervention and at follow-up (Peny-Dahlstrand et al., 2009; Steinhart et al., 2021). Better overall independence was also observed, as evaluated by the Wee-Functional Independence Measure (Wee-FIM) (Steinhart et al., 2021), but there were no changes in participation in daily life contexts (Peny-Dahlstrand et al., 2009).

When studying occupation-based therapy, Harr et al. (2011) observed an increase in the participant's performance in the Arc's Self-Determination Scale (SDS) and in the COPM, but a decrease in the score for in-home context activities, presented in the follow-up evaluations of the *Children Helping Out: Responsibilities, Expectations and Supports* (CHORES).

Among the studies that evaluated specific training, such as the wheelchair skills training program (WSTP), Sawatzky et al. (2012) observed an improvement in independence in wheelchair travel, but a decrease in community participation. When evaluating the training self-care in toilet activities, Donlau et al. (2013) observed improvement in the performance of the individual goals in the evaluation by the GAS but decreased the score in the COPM.

A large variability of evaluative methods was also found. However, it is worth noting that the COPM and GA emerged as the most prominent measures for defining individual goals, being utilized in a total of 8 studies. The results show that the scales that evaluated the individual goals were more sensitive to changes in outcome than general ADL independence measures (Driscoll et al., 2019; Harr et al., 2011; Holbein et al., 2013; Peny-Dahlstrand et al., 2009), which may be due to the difficulty of transferring and generalizing the learning of individuals with MMC, as learning a specific task does not represent a ability to generalize this learning to other tasks or other contexts (Peny-Dahlstrand et al., 2009).

Common elements of the interventions that favor their effectiveness were identified. Setting personal goals enables the inclusion of a heterogeneous population in terms of objectives, diagnoses, and disability severity as well as different contextual factors in a positive, dynamic and iterative process that takes into account what is important to each individual, identifying and creating significant objectives (O'Mahar et al., 2010; Peny-Dahlstrand et al., 2009). This increases the patients' motivation, perseverance and sense of self-efficacy during the intervention. According to Bovend'Eerdt et al. (2009), goals must have certain characteristics in order to effectively change behavior: they should be relevant to the individual in question, challenging but realistic and achievable, as well as specific and measurable, grouping these features under the acronym SMART (specific, measurable, achievable, realistic/relevant and timed).

Participation by parents and/or family members contributed to intervention success, since both patients and their families have difficulty adjusting to new roles and responsibilities and parents need to provide safe spaces for these changes to take place within the family's daily routine. Stern et al. (2020) investigated how parental behavior moderates the association between attention/executive function and independence in activities related to responsibility for SB management. The authors found that mothers and fathers can help their children take responsibility for self-management by providing a structured environment that supports autonomy and allows them to develop their executive function skills.

The use of cognitive learning strategies was another common element found in the interventions identified. Several studies demonstrated that individuals with MMC may present executive dysfunctions such as planning and problem-solving difficulties, which also compromises their ability to create and apply strategies effectively (Dennis & Barnes, 2010). Toglia et al. (2012) define cognitive strategies as a mental action plan and emphasize that their use can improve learning, problem solving and task performance in terms of efficiency, speed, precision and consistency.

Another important element was training the stages of activities in natural settings. According to Beckers et al. (2020), home-based programs offer a unique opportunity to continuously train specific tasks in a relevant setting, allowing parents to incorporate training into their daily routine and promoting generalized learning. This

can also be achieved via telerehabilitation, which refers to the use of information and communications technology to deliver rehabilitation services remotely. In 2014, the World Federation of Occupational Therapists recognized telerehabilitation as a suitable model for providing occupational therapy services, whereby telehealth is used to help patients develop skills; incorporate assistive technology and adaptive techniques; modify work, home or school setting; and create health-promoting habits and routines (Hung & Fong, 2019). In Brazil, this treatment format was authorized by the Federal Council of Physical Therapy and Occupational Therapy (COFITO) via resolution 516, of March 20, 2020, due to the coronavirus pandemic (Brasil, 2020). The present review identified 1 article that used synchronous care, with appointments via Skype, and 3 with an asynchronous format, via smartphone applications.

Nine studies featured educational groups as part of the intervention strategy. This is an important element because people with MMC are at risk of developing secondary conditions, such as intestinal and bladder problems, pain, fatigue, depression, obesity and pressure sores due to motor and sensory disorders. Dicianno & Wilson (2010) reported that one-third of hospitalizations of adults with SB were attributed to potentially avoidable secondary conditions.

Finally, although some studies have already shown that several specific conditions of the condition (injury level, motor and cognitive functions and presence of hydrocephalus) have an impact on the independence of individuals with MMC (Davis et al., 2006; Luz et al., 2017; Steinhart et al., 2021), the studies of this review did not find an effect of these characteristics on ADL independence.

A notable limitation of the study was the exclusion of articles that required purchase or subscription access to journals. This restricted access to potentially valuable sources of information, which could have contributed to a more comprehensive analysis. The reliance on freely available articles may have introduced a bias in the selection process, leading to the omission of relevant studies that were inaccessible due to financial or subscription barriers. It is important to acknowledge this limitation as it may have influenced the overall findings and conclusions of the study.

Conclusion

The present study achieved its objectives in identifying and analyzing evidence on interdisciplinary or occupational therapy interventions considered effective at promoting independence in ADLs and IADLs in individuals with MMC, their theoretical frameworks and components, such as: setting individual goals, participation by parents/family members, use of cognitive learning strategies, training stages of activities in natural settings, telerehabilitation and educational groups.

Further research with greater methodological rigor is needed to define the effectiveness of interventions to increase independence in ADL for individuals with MMC, in addition to evaluating the moderating effect of the level of injury, cognitive function and presence of hydrocephalus on the outcome of these interventions.

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