Effect of Spinal Muscular Atrophy Awareness Sessions on Premarital Clients' Willingness to Perform Comprehensive SMA Genetic Testing

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Abstract

Background: Premarital counselling in healthcare has a positive reflection on health and wellbeing of future families and inurn the whole community because it makes premarital clients feel energized, empowered with sufficient knowledge. Spinal muscular atrophy is caused by a deficiency of the ubiquitous protein survival of motor neuron. Comprehensive SMA genetic testing, combined with appropriate genetic counseling could be important preventive services. **Aim of the study:** was to examine the effect of spinal muscular atrophy awareness sessions on premarital clients' willingness of to perform comprehensive SMA genetic testing. **Design:** A quasi-experimental research design was utilized to achieve the aim of the study. **Subjects:** A total of 742 of premarital clients were participated in the study, a convenience sampling technique was utilized to involve participants. **Setting:** The study was conducted in the 6 medical centers which presents premarital services at Cairo Governorate including" Elamiria, Sakre Koraish, Elfagala, Eltebien, Alandalus, and Masr El-kadima childcare center". **Tools of data collection:** Two tools were used for data collection: Spinal Muscular Atrophy Knowledge Questionnaire, willingness to perform comprehensive SMA genetic testing scale. **Results:** After implementing awareness sessions, there was a highly statistically significant improvement in Spinal Muscular Atrophy knowledge of premarital clients(p=0.001). Furthermore, Spinal Muscular Atrophy awareness sessions positively correlated to premarital clients' willingness to perform comprehensive SMA Genetic Testing. **Conclusion:** Spinal muscular atrophy awareness sessions had a positive effect on premarital clients' willingness to perform comprehensive SMA Genetic Testing. **Recommendations:** Ministry of Health should apply Spinal muscular atrophy awareness sessions as a part of premarital counselling to help in decreasing disease

Key words: Awareness sessions, Comprehensive SMA Genetic Testing, Spinal muscular atrophy. incidence.

Background

Egyptian Ministry of Health is concerned with presenting premarital counseling services that encompasses a consultation process through which present, past and family history is collected, medical examination as well as laboratory investigations performed to premarital clients. Pre-marital investigations are conducted to discover inherited and transmitted medical conditions. Premarital genetic counseling minimizes the likelihood of having children with a medical problem by identifying the need for therapy or assisting the couple in deciding whether or not to avoid pregnancy in case of an elevated risk of abnormalities **(Anestis, et al., 2020)**.

Spinal muscular atrophy (SMA) is an autosomal recessive neuromuscular disorder defined by the loss of alpha motor neurons in the spinal cord, which causes gradual proximal muscle weakening and paralysis **(Levine, et al., 2024)**. SMA is characterized by alterations in

the SMN1 gene, which produces a protein required for motor neuron survival. Prevalence of the disease is around 1-2 per 100,000 individuals as well as an incidence of approximately one in 10,000 live births have been estimated **(Lagae, et al., 2024).**

Symptoms of spinal muscular atrophy (SMA) includes muscle weakness and decreased tone, difficulty with crawling, walking, or even sitting up independently can occur, breathing difficulties, feeding difficulties, spontaneous tongue movements (Fasciculations) characterized by involuntary twitches which can be a sign of nerve damage. Also, Spinal curvature could be developed due to muscle weakness affecting the back muscles **(Kimizu, et al., 2021)**.

There are symptoms that could be specifically accompanied by certain types of spinal muscular atrophy **(Motta, et al.,2021).** The first is " SMA type 0" which is very severe, its symptoms pronounced before birth, encompassing extreme weakness and breathing difficulties. Second type is " SMA type 1" which is called "Werdnig-Hoffmann disease". It is the most common type which is severe, often evident before 6 months of age, with severe muscle weakness, breathing and feeding difficulties **(Nurputra, et al.,2021).**

Furthermore, the third is "SMA Type 2" characterized by symptoms that is recognized between 6 and 18 months, with children able to sit but not stand or walk unaided. The fourth type is "SMA Type 3" or is named "Kugelberg-Welander disease" **(Strauss, et al.,2022)**. Its symptoms appear after 18 months, with children able to walk but may have difficulty with stairs or running. The last type is "SMA Type 4", its symptoms develop after 18 years of age, with mild to moderate leg muscle weakness **(VanKruijsbergen, et al.,2021)**.

Other potential symptoms could include tremors or twitching in their hands or tongue. Feeling easily fatigues which can impact daily activities, joints can become fixed in certain positions due to muscle stiffness in addition to foot deformities such as feet turn inward or be otherwise misshapen **(Weaver, et al.,2020)**.

Preventive testing for spinal muscular atrophy (SMA) is of vital importance since it permits for early exploration of the disorder, which can lead to earlier intervention and potentially superior outcomes for patients. Premarital carrier screening for Spinal Muscular Atrophy (SMA) is accessible and advised, particularly for clients who intend to have children. This test identifies if individuals are carriers of the SMA gene, which can inform reproductive decisions **(Yao, et al., 2021).**

After applying preventive testing for spinal muscular atrophy (SMA), if one premarital individual is a carrier, genetic counseling is of an urgent priority as it can help to understand the implications and potential treatment options; Additionally, the other partner should also be tested. If both clients are carriers, prenatal testing may be considered during pregnancy **(Yang, et al., 2023).**

Support and advocacy are considered the central role of community nurse. The community nurse by raising awareness about spinal muscular to atrophy assist in preventing disease stigma and supporting individuals and families in case they were affected by the disease. Community nurses should fight for fundraising for research, advocating for better access to care and treatment, and promoting inclusive practices in communities. Various scientific conferences, workshops and initiatives should be organized to foster a sense of community awareness to spinal muscular to atrophy. Other forms of community awareness could include online campaigns, local events, and opportunities to share stories and experiences **(Baranello, et al., 2021).** So this study was conducted to explore the effect of spinal muscular atrophy awareness sessions on premarital clients' willingness to perform comprehensive SMA diagnostic tests.

Research significance:

Egypt vision 2030 emphasized on preventive rather than curative healthcare services. This vision ensures efforts to battle Spinal Muscular Atrophy (SMA), a hereditary condition, with a focus on early diagnosis and treatment. This includes a presidential move to establish 24 clinics nationally to care for

children with SMA and provide access to gene therapy. The effort is consistent with Egypt's Vision 2030 goals, which prioritize human-centered development, equity, and sustainability. **(Ministry of Health, 2025).**

Studying the effect of spinal muscular atrophy awareness sessions on premarital clients' willingness of to perform comprehensive SMA genetic testing has been studied in various researches, pronouncing its special relevance in community nursing practice **(Hjorth, 2020)**. Studies revealed that high levels of willingness of to perform comprehensive spinal muscle atrophy genetic testing are associated with awareness sessions and health education by community nurses which results in early detection and disease prevention **(Fernandes, et al., 2022; Kimizu, et al. ,2021; Lagae, et al., 2024).**

In 2021, President Abdel Fattah El-Sisi launched an initiative to treat SMA patients, including providing gene therapy and allocating 24 clinics for diagnosis and treatment which are still serving the community **(Motta & Paulo,2020)**. This research emphasized the importance of comprehensive SMA genetic testing during premarital services as a crucial preventive measure which was supported by previous studies conducted by **(Levine, et al.,2021; Yang, et al., 2023).** Moreover, other research studies ensured that the incidence of this disease was 1 in 24100 live births and prevalence was 1.20 per 100,000 of the general population **(Lagae, et al., 2024).**

Aim of the study:

This study aimed to examine the effect of spinal muscular atrophy awareness sessions on premarital clients' willingness of to perform comprehensive SMA genetic testing through the following objectives:

1- Assessing premarital clients' knowledge about spinal muscular atrophy

2- Assessing premarital clients' willingness to perform comprehensive SMA genetic testing

3- Designing and Implementing awareness sessions about spinal muscular atrophy for premarital clients.

4- Evaluating the influence of awareness sessions on premarital clients' willingness to perform comprehensive SMA genetic testing.

Research Hypothesis

The current study hypothesized that awareness sessions about spinal muscular atrophy will improve premarital clients' willingness to perform comprehensive SMA genetic testing.

Methods

Research design: One group pretest-posttest quasi experimental research design was used to carry out this study.

Research setting: The study was performed at conference room of the 6 medical centers which presents premarital services at Cairo Governorate including" Elamiria, Sakre Koraish, Elfagala, Eltebien, Alandalus, and Masr El-kadima childcare center".

Sampling: The G Power software was used to determine the sample size, which had a medium effect size, 0.04 alpha, and 0.97 power. The necessary sample size to carry out the present study was 400 premarital clients and increased to 742 out of 407 for the possibility of attrition with response rate 100%. A convenience sampling technique was utilized to involve participants from the previously mentioned settings.

Sample Criteria: Researchers included in the study all premarital clients who have premarital services in the current research setting, of both genders, and exclude those who attend previous awareness sessions about spinal muscular atrophy.

Instruments Two tools were used for data collection: Spinal Muscular Atrophy Knowledge Questionnaire, willingness to perform comprehensive SMA genetic testing scale.

Tool 1: Spinal Muscular Atrophy Knowledge Questionnaire. It consists of two parts:

Part I: Premarital Clients' Personal Data. This part portrayed information on participants' demographic characteristics, including age, level of education, and monthly income.

Part II: Spinal muscular atrophy knowledge questionnaire: Developed by the researchers after reviewing literature of previous studies **(Yang, et al., 2023; Fernandes, et al., 2022; Kimizu, et al. ,2021 & Lagae, et al., 2024)**. It encompasses (20) multiple-choice questions. The topics covered the following domains: Definition of spinal muscular atrophy disease, causes, diagnosis, signs and symptoms, types, diagnostic tests, treatment, possible complications, and preventive measures.

Each question was scored as "2" for a correct answer and "1" for an incorrect response. The total score for the questionnaire was (40) points. The cutoff point was calculated using - Receiver Operating characteristic (ROC) Curve. The scoring system was categorized as follows: (less than 75%) were deemed unsatisfactory. (75% or higher) were considered satisfactory.

Tool 2: Willingness to Perform Comprehensive Spinal Muscular Atrophy Genetic Testing Scale: It was designed by Developed by the researchers after reviewing literature of previous studies (**Levine, et al., 2024; Bagga, et al.,2024 &Lagae, et al., 2024).** It aimed at assessing premarital clients' beliefs regarding comprehensive spinal muscular atrophy genetic testing including 10 items using three points Likert scale (1-3). The tool was translated into Arabic.

Scoring System: Each statement was scored as (3) for agree, (2) for neutral and (1) for disagreement, the total score was calculated by the sum of each statement and converted into a percent to be categorized into:

• High willingness if scores were ≥ 70% (≥21 marks).

• Moderate willingness if scores were 50%-70% (15-20 marks).

• Low willingness if scores were ≤ 50.0% (<15 marks).

Pilot study:

Before starting the main fieldwork, a pilot study involving at the study setting,40 of premarital clients which composed 10% of the total study sample. The pilot study aimed to assess the feasibility, practicality, and clarity of the language used in the tools of data collection. No modifications were required, so, the pilot study was included in the study.

Tool validity and reliability:

Initially, a certified bilingual translator independently translated the English tools into Arabic to create the initial Arabic versions. Subsequently, the first researcher re-translated these initial Arabic versions back into English and compared them with the original tools to ensure semantic equivalence. This rigorous process aimed to maintain the integrity of the translated versions while minimizing discrepancies between the original and translated tools.

Validity of tools was examined for face and content by panel of jury group. This group was consisted of 3 professors and 2 assistant professors specialized in Community Nursing working at Faculty of Nursing- Tanta University, and Helwan University. Jury group examined tools carefully to judge its clarity, comprehensiveness and accuracy. Their opinions were elicited about the tools layout, components and scoring system. According to jury opinions the researchers modified minor items from the tools such as rephrasing some items and rearranging some items to be more accurate and clearer.

Data collection tools were assessed its reliability through measuring its internal consistency by using Cronbach's Alpha Coefficient test. The values obtained were 0.89 for the spinal muscular atrophy knowledge questionnaire, 0.91 for the Willingness to Perform Comprehensive Spinal Muscular Atrophy Genetic Testing Scale. According to (10), Cronbach's alpha values exceeding 0.7 are deemed acceptable for demonstrating internal consistency reliability.

Ethical considerations:

The Research Ethics Committee (REC) at the Faculty of Nursing, Modern University for Technology and Information (MTI), granted approval for the study. Also, an official letter outlining the study's title and objectives was sent from the Dean of the Faculty of Nursing to the directors of the 6 medical centers which presents premarital services at Cairo Governorate including" Elamiria, Sakre Koraish, Elfagala, Eltebien, Alandalus, and Masr El-kadima childcare center" to secure authorization from the medical centers' administrators for data collection. Additionally, written consent for participation was obtained from the study participants after providing comprehensive information about the study.

Fieldwork:

The main data collection for the study took place between September 2024 and May 2025. The research process encompassed various phases including assessment, planning, implementation, and evaluation. The study was carried out on the following phases.

Phase I (Assessment Phase): During the assessment phase, the initial step involved administering Spinal Muscular Atrophy Knowledge Questionnaire to assess premarital clients' knowledge about Spinal Muscular Atrophy, using "tool I". Then Tool II was distributed to participants to identify their willingness to perform comprehensive Spinal Muscular Atrophy genetic testing. Data collection occurred during participants' presence at the study setting. The researcher was available to offer guidance and clarification as needed and gathered the completed tools immediately after their completion. Completion time for questionnaire sheets ranged from 15 to 20 minutes for tools I and II.

Phase II (Planning): The planning phase was prepared based on an analysis of the assessment phase results and relevant literature. Prior to starting the study, the content validity of the awareness sessions was assessed by estimating the content validity index (CVI). A panel of five experts, comprising five nursing academics, participated in the validation process. The experts evaluated the clarity and relevance of the study tools and offered recommendations to enhance their quality. The resulting CVI for the study awareness sessions was determined to be 0.95, indicating strong content validity. The awareness sessions' content and teaching methods were carefully chosen. Additionally, the researcher designed the time schedule, teaching sessions, and selected appropriate media for instruction. The teaching methods encompassed lectures, group discussions, and real-life examples, supplemented by visual aids such as data shows and handouts. This phase of program development was completed within a span of two weeks.

Phase III (The awareness sessions implementation): the researcher applied the awareness sessions. All study participants attended two sessions, with each session lasting one hour in morning shift. They perceived the awareness sessions contents using teaching strategies. Various teaching methods were used, including lectures, group discussions, and brainstorming. Instructional materials consisted of videos, in addition to PowerPoint presentation for awareness sessions. The sessions addressed key topics related to spinal muscular atrophy, including definition of spinal muscular atrophy disease, causes, diagnosis, signs and symptoms, types, diagnostic tests, treatment, possible complications, and preventive measures.

Phase IV (Evaluation phase): In the evaluation phase, Tool I was employed directly after the application of the awareness sessions to assess premarital clients' knowledge levels about spinal muscular atrophy. Tools II, was then distributed post- awareness sessions' conduction to measure premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing.

Statistical Analysis:

The data collected were thoroughly revised, coded, and organized prior to entry into IBM SPSS Statistics software (version 26.0). For parametric numerical data, we calculated the mean, and standard deviation (± SD). Frequencies and percentages were also computed to summarize premarital clients' knowledge related to spinal muscular atrophy

pre and post implementation of awareness sessions. Chi-square tests (X^2) were utilized to assess differences in knowledge between two phases. Significant differences were indicated by p-values, with $p \leq 0.05$ considered significant and $p \leq 0.01$ regarded as highly significant. Linear regressions were performed to reveal the effect of spinal muscular atrophy awareness sessions on premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing. The reliability of the study's tools was evaluated using Cronbach's alpha coefficient, to identify internal consistency.

Results

Distribution of study subjects according to their Personal Data (n=742).

Table 1 explains that the study sample consisted of 742 premarital clients with equal percent (50%) of both genders. More than half of nurse managers (53.2%) aged between 30 to less than 40 with a mean ± SD (30.95 ± 6.54). Less than half (49.9%) had a university education. Additionally, the majority (92.9%) don't have enough monthly income.

Relation between study variables

Premarital clients' knowledge about spinal muscular atrophy pre and post implementation of awareness sessions.

As illustrated in table (2) prior to awareness sessions implementation, only (1.1%) of studied premarital clients had satisfactory total knowledge regarding spinal muscular atrophy. However, following the awareness sessions, the majority (95.9%) had a high total satisfactory knowledge level. There was a significant and positive improvement in their knowledge levels related to all dimensions and total spinal muscular atrophy compared to pre-awareness sessions levels (P<0.001).

Premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing pre and post awareness sessions' implementation.

Table 3 depicts a notable and statistically significant improvement in premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing pre and post awareness sessions' implementation (p value 0.000**).

The effect of Total Spinal muscular atrophy knowledge on premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing pre and post awareness sessions.

Table 4 portrays that there was a statistically significant positive predictor from premarital clients' knowledge about spinal muscular atrophy and their willingness to perform comprehensive spinal muscular atrophy genetic testing (p = <0.00).

Table (1): Personal data of studied subjects (n=742)

Personal data items	Premarital clients (n= 742)	
	No.	%
Age in years		
20< 30	322	43.4
30 < 40	395	53.2
>40	25	4.3
Gender		
Male	371	50
Female	371	50
Mean±SD 30.95±6.45		
Level of education		
Illiterate	9	1.2
Basic education	100	13.5
Intermediate education	263	35.4
University education	370	49.9
Monthly income		

Personal data items	Premarital clients (n= 742)	
	No.	%
Not enough	689	92.9
Enough	14	1.9
Enough and save	39	5.2

Table (2): premarital clients' knowledge level about spinal muscular atrophy pre and post implementation of awareness sessions (n=742).

Spinal muscular atrophy (SMA) Knowledge Dimensions	Satisfactory knowledge (≥ 75%) (n=742)								Pre -post	
	Pre- awareness sessions				Post awareness sessions					
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory		χ^2	P-value
	No.	%	No.	%	No	%	No	%		
1. Definition of spinal muscular atrophy disease.	41	5.5	701	94.5	711	95.8	31	4.2	20.68	0.000**
2. Causes of SMA.	10	1.3	732	98.7	739	93.1	51	6.9	20.36	0.001**
3. Diagnosis of SMA.	8	1.1	734	98.9	741	99.9	1	0.1	9.898	0.001**
4. signs and symptoms of SMA.	5	0.7	737	99.3	709	95.6	33	4.4	19.507	0.000**
5. Types of SMA.	1	0.1	741	99.9	699	94.2	43	5.8	18.26	0.001**
6. Diagnostic tests of SMA.	3	0.4	739	99.6	692	93.3	50	6.7	14.44	0.001**
7. Treatment of SMA.	1	0.1	741	99.9	733	98.8	9	1.2	12.50	0.001**
8. Possible complications of SMA.	1	0.1	741	99.9	720	97	22	3	9.02	0.001**
9. Preventive measures of SMA.	2	0.3	740	99.7	710	95.7	32	4.3	20.36	0.001**
Total Knowledge level	8	1.1	734	98.9	712	95.9	30	4.1	18.59	0.001**

*Significant at p ‹ 0.05 **highly significant at p ‹ 0.01.

Table (3): Premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing pre and post awareness sessions' implementation (n=742).

Willingness items	Pre- awareness sessions						Post awareness sessions							Pre-post
	High		Moderate		Low		High		Moderate		Low		χ2	p value
	N.	%	No.	%	N.	%	N.	%	N	%	N	%		
1. I believe that, protection is better than cure.	350	47.2	181	24.4	211	28.4	641	86.4	50	6.7	51	6.9	30.94	0.0001**
2. I am willing to perform comprehensive SMA genetic testing.	22	3	10	1.3	700	95.7	720	97	20	2.7	2	0.3	46.78	0.0001**
3.I am willing to encourage relatives and friends to perform comprehensive SMA genetic testing.	10	1.3	12	3.0	700	95.7	710	95.7	30	4.0	2	0.3	0.895	0.0001**
4. I will talk to my family about comprehensive SMA genetic testing results when I perform it.	20	2.7	9	1.2	713	96.1	699	94.2	40	5.4	3	0.4	0.942	0.000**
5. I think that preventive testing (SMA) is of vital importance.	17	2.3	40	5.4	685	92.3	690	93	49	6.6	3	0.4	0.588	0.0001**
6. I think that all premarital clients should perform comprehensive SMA genetic testing.	15	2.0	45	6.1	862	91.9	685	92.4	53	7.1	4	0.5	0.011	0.0001**
7. I think that premarital carrier screening for (SMA) is accessible and advised, particularly for clients who intend to have children.	60	8.1	40	5.4	642	86.5	680	91.6	58	7.9	4	0.5	0.676	0.000**

Willingness items	Pre- awareness sessions						Post awareness sessions							Pre-post
	High		Moderate		Low		High		Moderate		Low		χ2	p value
	N.	%	No.	%	N.	%	N.	%	N	%	N	%		
8. I believe that if individuals are carriers of the SMA gene, they should inform reproductive decisions.	40	5.4	42	5.7	680	88.9	641	86.4	50	6.7	51	6.9	0.663	0.000**
9. I believe that if one premarital individual is a carrier, genetic counseling is of an urgent priority.	30	4.0	22	3.0	690	93	700	94.3	40	5.4	2	0.3	0.792	0.000**
10. I believe that if two premarital individuals are carriers, prenatal testing will be a must during pregnancy.	10	1.3	52	7.0	680	91.7	710	95.7	30	4.0	2	0.3	0.764	0.000**
Total	57	7.7	45	6.1	640	86.2	688	92.7	42	5.7	12	1.6	42.87	0.0001**

*Significant at p ‹ 0.05 **highly significant at p ‹ 0.01.

Table (4): Simple linear regression for the effect of Total Spinal muscular atrophy knowledge on premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing pre and post awareness sessions (n=742).

Model	premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing									
	Pre-awareness sessions					Post awareness sessions				
	Liner regression					Liner regression				
(Constant) Total	B	r	R^2	Std. Error	t(sig)	B	r	R^2	Std. Error	t(sig)
Spinal muscular atrophy knowledge among premarital clients	.227	.226	**.09**	.129	2.962 (.03*)	.66	.91	**.83**	.043	0.667 (.000**)

Discussion

Spinal muscular atrophy (also known as SMA) describes an uncommon, fatal hereditary condition which impacts neurons that control movement in the spinal cord, causing muscle atrophy and deteriorating. This illness has gained considerable interest in recent years due to the emergence of revolutionary medicines, such as gene-based treatments, that have the ability of improving the prognosis among those diagnosed with SMA **(Bagga, et al.,2024)**. Previous researches high lightened the negative effects of SMA on individuals and healthcare systems. An integrated strategy is required, including complete support services, caregiver health training and education, psychosocial support services, financial support programs, and healthcare system improvements to enhance use of specialized medical service **(Levine, et al.,2021; Yang, et al., 2023).** The present research explored examine the effect of spinal muscular atrophy awareness sessions on premarital clients' willingness of to perform comprehensive SMA genetic testing. Present results suggested a significant positive improvement in studied premarital clients' knowledge levels related to all dimensions and total spinal muscular atrophy compared to pre-awareness sessions levels (P<0.001). From the researchers' point of view, this result was encouraging and ensured the importance of premarital clients' awareness sessions about SMA to the wellbeing of individuals and community.

(Antonaci, et al., 2023) supported present results in their study titled " New therapies for spinal muscular atrophy: where we stand and what is next ". They found that a significant improvement in participants' knowledge post awareness sessions resulted in higher levels of understanding the wide prevalence of disease, its occurrence, and natural evolution. Also, the study conducted by **(Kimizu, et al.,2021)** entitled " Spinal Muscular Atrophy: Diagnosis, Incidence, and Newborn Screening in Japan" supported present study results and declared that the majority of study participants had a high total satisfactory knowledge level post awareness sessions' implementation resulting in a significant improvement in their cooperative level at early detection and intervention for this devastating genetic disorder of SMA.

Genetic testing is considered the most reliable method for diagnosing SMA. It gives an accurate diagnosis, reveals the exact mutation in genes, and can assist in determining the extent of the clients' severity **(Hjorth, et al.,2020)**. Present study results verified statistically significant improvement in premarital clients' willingness to perform comprehensive spinal muscular atrophy genetic testing pre and post awareness sessions' implementation (p value 0.000**). From the researchers' opinion, awareness sessions about SMA give clients the opportunity to realize the importance of comprehensive SMA genetic testing as a predictor for disease recognition. Participants recognized that early detection of disease carriers before conception give the opportunity to avoid disease occurrence. Present results were in the same line with the results of **(Lagae, et al., 2024)** in their study about " Respiratory

morbidity in patients with spinal muscular atrophy—a changing world in the light of disease-modifying therapies " they reported that study sample desire to perform SMA genetic tests had improved significantly post awareness sessions and is negatively correlated to the respiratory morbidity in patients with spinal muscular atrophy.

On the same line **(Levine, et al.2023)** in their study entitled " Evaluation of sputum cultures in children with spinal muscular atrophy" reported a high level of willingness to perform sputum cultures in children with spinal muscular atrophy post awareness sessions. Additionally, **(Nurputra, et al.,2022)** in their study entitled" Spinal Muscular Atrophy: From Gene Discovery to Clinical Trials" who found that post awareness sessions, the majority of study participants had the willingness to perform comprehensive spinal muscular atrophy genetic testing. In accordance with present study results, **(Weaver, et al.,2020)** who studied " A prospective, crossover survey study of child- and proxy-reported quality of life according to spinal muscular atrophy type and medical interventions" found that the awareness sessions conducted to study participants raised the level of genetic diagnostic tests application up to 90% and affects their quality of life positively.

Present results depicted that there was a statistically significant positive predictor from premarital clients' knowledge about spinal muscular atrophy and their willingness to perform comprehensive spinal muscular atrophy genetic testing ($p = <0.00$). From the researchers' opinion, this may be related to the instructions and explanations of the researcher to premarital clients about the importance of genetic tests application as a part of preventive role in the community. Premarital clients who participated in the study were informed by the researcher in their awareness sessions about presidential initiative to prevent SMA, and that early detection of the disease is available at 25 clinics allover Egypt and these services are free (MOH,2025). Additionally, the researcher explained the Definition of spinal muscular atrophy disease, causes, diagnosis, signs and symptoms, types, diagnostic tests, treatment, possible complications, and preventive measures.

Present results were supported by **(Yang, et al.,2023)** in a study titled " Safety and efficacy of gene therapy with osmogene approved in the treatment of spinal muscular atrophy: a systematic review and meta-analysis " reported the same results but, the awareness sessions' effect on SMA genetic testing importance perception and willingness was introduced and treated as an independent variable. Their results showed that the awareness sessions about SMA had a positive and significant relationship with participants' perception and willingness to apply SMA genetic diagnostic tests. On the other hand, **(Fernandes, 2022)** who conducted a study about " Communicating the Spinal Muscular Atrophy diagnosis to children and the principle of autonomy " contrasted present study results when found that willingness to perform SMA genetic tests becomes statistically insignificant with an increase in the R-square by 0.067 ($p < 0.001$).

Conclusion

In the light of present research findings, it can be concluded that there was a significant and positive improvement in premarital clients' knowledge related to all dimensions and total spinal muscular atrophy compared to pre-awareness sessions application levels ($P<0.001$). Finally, the study findings revealed that spinal muscular atrophy awareness sessions had a positive effect on the willingness to perform SMA genetic tests among premarital clients.

Recommendations

Based on the current study findings, the following recommendations were suggested:

Medical centers should:

- Provide community nurses with training programs about SMA to promote their educational role in the community.
- Afford adequate resources and financial support to apply SMA awareness sessions to their clients.

Community nurses should:

- Develop their knowledge and skills related to SMA by attending conferences,

workshops and available training about the topic.

- Practice their advocacy and support role to clients diagnosed by SMA .

- Be aware of available MSA healthcare services and inform community members to make use of it**.**

Educational organizations should:

- Introduce spinal muscular atrophy into undergraduate nursing education.

Furthers studies:

- Developing spinal muscular atrophy nursing care guidelines to improve quality of life .

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