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Effects of chronic disease self – management program on quality of life and wellbeing among chronic ill adolescents at Majmaah university female Colleges, KSA.

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ABSTRACT

Back ground

Chronic disease Self- management program is an important issue in health today which emphasize patient role in decision making, care, minimize health cost and expenditure. Chronic illness represents challenging for adolescents and their families which need active patient participation and continuous medical care to overcome their complications and improve chronic illness prognosis.

Aim

This study aimed to assess effects of chronic disease self-management program on quality of life and wellbeing among chronic ill adolescents at Majmaah university female Colleges.

Sample

All diagnosed chronic ill adolescent at Majmaah University female Colleges under certain criteria were included in the study their number were 40.

Setting

The study was conducted at Majmaah university female Colleges, data were collected from 1st of November 2013 to the end of May 2014, data collected before the program, after program (immediately post) and at follow up (after 3months from the program).

Results

The present study revealed that chronic disease self- management program has a great impact in study subjects' knowledge; quality of life and wellbeing level with significant change were found post the program.

Conclusion

Chronic disease self-management program (CDSMP) represent a core component of chronic disease management which seek to empower adolescent to deal with the disease and live better quality of life with fewer restriction from their chronic illness.

Keywords: Chronic Disease Self-Management Program (CDSMP), Quality of Life, Wellbeing, Chronic Ill Adolescent, Majmaah University Female Colleges

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REVIEW OF LITERATURE

Chronic Disease Self-Management Program (CDSMP) is a program given to the chronic ill individual to increase their ability to manage; their symptoms, treatment, physical and psychosocial consequences of the disease and life style changes inherent in living with a chronic condition.[1] Chronic illness are a long lasting health conditions that develop slowly and get worse over a time. Adolescence is a period of rapid growth.[2] It is a time of learning about and understanding bodies, at this time it is natural to be concerned with body image.[3] The definition of the period of adolescence is different from one country to another; American Medical Association and the American Academy of Pediatrics define adolescents as those persons 11 to 21 years of age. The World Health Organization had considered 10 to 19 years as the period of adolescence.[4]

The diagnosis of chronic illness during adolescent period will affect the life of the adolescent and all family members. Living with chronic illness present a hard challenges to the adolescents and their families.[5] The adolescent who has just been diagnosed with chronic illness may feel vulnerable, confused, worried about their health and their future and other may feel sad or disappointed in their bodies.[6,7] They also may experience increase difficulties in variety of areas as social relationships, body image and non-compliance with the management plan.[8]

Chronic illness during adolescence has significant psychological and social consequences within a broad range of life domains.[9] While adolescents with a chronic illness deal with the usual physical, social and psychological changes of puberty, they also face the on-going demands of illness management.[10] At a time when there is naturally a move towards increasing independence from the family, chronic illness may force a greater dependence on the family.[11] Moreover, illness that results in school or university absence can interfere with the formation of stable peer networks, increasing a sense of social isolation.[12] It is important to develop effective ways of building resilience in adolescent with a chronic illness, not only to prevent poor adjustment outcomes but also to promote positive well-being and improve quality & enjoyment of life.[13] The incidence of chronic conditions is rising in most developed and developing countries and will constitute the main cause of death by 2020,[1] among children, and especially among adolescents.[14] The management of any chronic condition during adolescence constitutes a major challenge for the individual, his/her family and the health-care team.[15]

The World Health Organization defined Quality of Life as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.[16] Well-being for adolescent mean self-esteem, trust and satisfaction, feeling well was equal to feeling capable, feeling happy and feeling a sense of community. People with higher levels of well-being judge their life as going well. People feel very healthy and full of energy to take on their daily activities. Personal factors, social circumstances, and community environments influence individual well-being level.[17,18]

MAGNITUDE OF PROBLEM

Living with chronic illness represent a hard challenging for the adolescent so chronic disease self-management program aimed to help the study subject to take active role in managing their problems and maintain control over their life through improving their knowledge, coping abilities, adherence to management plan and quality of life which in consequently improve their wellbeing level.

SUBJECT AND METHODS

Aim

This study aimed to assess effects of chronic disease self-management program on quality of life and wellbeing among chronic ill adolescent at Majmaah university female Colleges.

Research questions

(1) Is the adolescents' knowledge about chronic illness will be improved significantly post the chronic disease self-management program?

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(2) Is the adolescents quality of life will be improved significantly post the chronic disease self-management program?
(3) Is the adolescents wellbeing level will be improved significantly post the chronic disease self-management program?

Type of study
It is an intervention study.

Design
Quasi experimental research design was used.

Sampling
Purposive sample of all diagnosed chronic ill adolescent at Majmaah university female Colleges under the following criteria; willing to participate in the study, be physically able to attend the program sessions, able to provide self-management care and free from complications, their number were 40 and their ages ranged from 17-21 years. Data were collected from 1st of November 2013 to the end of May 2014.

Setting description
Majmaah University has established in 3 Ramadan 1430, it has 7 Colleges in Majmaah governorate 3 of them were female Colleges (education, computer& applied medical science College).

Tools
Data were collected through
(1) Questionnaire sheet which include 4 parts:
    a) Socio demographic data (College name, age, father employment & number of siblings).
    b) Impact of chronic illness in College attendance (attendance & number of monthly absenteeism days due to chronic illness).
    c) Clinical data of the studied subjects (diagnosis, disease duration, hereditary factor, no of yearly hospital admission & chronic illness manifestations.
    d) Adolescent knowledge about the disease (definition, causes, treatment, care, special food, special diet and complications). This part was used before the program, after the program, at follow up (3 months post the program).
(2) Quality of life Index:
    (a) The researchers were adopted this tool from Carol &Marjorie (1998)[19] quality of life index diabetic version-III, The researchers were modified the tool and translate it into Arabic language to accommodate the study aim.
    (b) It consists from two main subscales; the 1st subscale consists from 34 items which reflect adolescents' level of satisfactory toward certain area of his life, it use a 6 point likert scale ranged from 1-6 (the responses ranged from very dissatisfied, moderately dissatisfied, slightly dissatisfied, slightly satisfied, moderately satisfied and very satisfied). The total score will become 204, the responses were sum {poor satisfaction level 1 - 67, average satisfaction level from 68-136 and high satisfaction level from 137- 204). The 2nd subscale consists from 34 items which reflect the level of importance of certain life aspects to study subject, it use a 6 point likert scale ranged from 1-6 (the responses ranged from very unimportant, moderately unimportant, slightly unimportant, slightly important, moderately important and very important). The total score will become 204, the responses were sum {poor importance level 1 – 67, average importance level from 68-136 and high importance level from 137- 204). The quality of life Index was used before the program, after the program, at follow up (3 months post the program).
(3) Wellbeing Assessment tool:
    (a) The researchers adopted this tool from the McKinley Health Centre at the

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University of Illinois (2005).[20] It was translated into Arabic language by the researchers to accommodate the study aim. It include 5 health subscales (Physical health, Social health, Emotional health, Spiritual health and intellectual health).Each subscale encompasses 10 items. The responses are ranged from very unhealthy, somewhat unhealthy, somewhat healthy, and end with very healthy (1-4). For each subscale the responses were sum poor well-being level 1-13, average well- being level14-27, high well – being level 28-40. (This tool was used before the program, after the program, at follow up (3 months post the program).

(b) Quality of life index and wellbeing assessment tool were handed to 2 professors of pediatric nursing to assess the coverage, relevancy and validity.

Ethical considerations:

Confidentiality of information was guaranteed for each study subject. A written agreement was a prerequisite for each study subject.

Administrative design:

An official permission was obtained from deans of the Colleges before conducting the study.

Pilot study:

A pilot study was carried out on 5 chronic ill adolescents to test the clarity and simplicity of the questions. Necessary modifications were done by exclusion of some items. Adolescents who shared in pilot study were excluded later from the main study sample.

Methods:

(1) A review of local and international related references was carried out to get acquainted with the various aspects of the research problem and the study tools. The questionnaire sheet was developed based on the literature review.

(2) Data were collected from 1st of November 2013 to the end of May 2014. Before the program, after the program and at follow up after 3 months from the program. All diagnosed chronic ill adolescent females involved in the study were interviewed in their Colleges according to their studying schedule in praying break time & activity lecture for 14 hours in 7 sessions. One session weekly for each College starting by education College each Sunday, computer College each Monday and applied medical science each Tuesday. 3 sessions weekly for the three Colleges.

(3) Chronic Disease Self-management Program (CDSMP) :

a) It was developed by the researchers based on the study aim, subjects' needs, readiness to accept the program, and the review of the related literature.

b) Aim: it aimed to help the adolescent to take active role in managing their problems and maintain control over their life through improving their' knowledge & health awareness level, coping abilities, quality of life and wellbeing level.

c) Theoretical part: include knowledge about; meaning of chronic illness, heredity factor , incidence of most common chronic illness in Saudi Arabia, causes & classification of chronic illness, impact of chronic illness on adolescent physical and psychological health, family & community, economic cost of management of chronic illness, it also address importance of adherence to management plan & follow up schedule. It give attention to meaning of health awareness, how to improve their level of health awareness also include knowledge about quality of life meaning, how to modify life style to cope with the disease, relaxation techniques, effective way of communication and

meaning of wellbeing. The program has sufficient knowledge about each diagnosis, its management plan and the adolescents' active role in management. It gives a great attention to daily problems and how to manage for each diagnosis.

d) Practical part: it concerned with demonstration of; life style modification, daily living activity, suitable exercise, relaxation techniques, effective way of communication with family & friends, how to manage their sleep and fatigue problems& diet, example of adherence to management plan according to each diagnosis, how to read & interpret written health instruction & each drug dose calculation, practical drugs administration, investigate side effect of each drug& precaution for each drug. The practical part of the program was lengthy and comprehensive; the researchers demonstrate video tips about exercise& diet for each illness. Also role play was used to solve heath awareness limitation and daily problems for each disease.

e) Several educational methods were used as group discussion, role play, demonstration and re-demonstration as well as, visual aids were used as posters, handouts, booklets about each diagnosis& its care was given to the adolescent at the beginning of the program.

f) The program was implemented in simple Arabic language in 7 sessions. 1st session for orientation, the study aim, incidence of chronic illness, impacts of chronic illness, self - management program, filling the tools (pre- test) and sign the informed consent, 2nd&3rd session for all theoretical information, 4th&5th sessions for practical parts, 6th session for revision, answering questions, investigate how they solve their day to day problem, re-demonstration of daily problem solving.7th session for ending the study and immediately post-test were done. Follow up post-test were carried out 3months post the program in study subject Colleges.

Statistical analysis:

The collected data were organized, tabulated and statistically analyzed using SPSS version 19 (Statistical Package for Social Studies) created by IBM, Illinois, Chicago, USA. For categorical variable the number and percentage were calculated and differences between subcategories before and after the program were tested using Wilcoxon singed ranks test. The level of significant was adopted at $p<0.05$.

RESULTS:

Table 1 represent socio-demographic characteristics of the studied subjects about half of the studied subject (45%) were from Education College and more than half of them their father were working (57.5%).

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Table 1 Socio-Demographic Characteristics of the Studied Subject

Variables	Number (n=40)	%
College:		
Education.	18	45.0
Computer.	14	35.0
Applied Medical science.	8	20.0
Age in years:		
17-	19	47.5
19-	17	42.5
21-	4	10.0
Fathers' employment:		
Working	23	57.5
Not working	17	42.5
Number of siblings:		
None	1	2.5
2-	6	15.0
4-	8	20.0
6-	11	27.5
8-	7	17.5
10+	7	17.5

Table 2 reflect the impact of chronic illness on college attendance among the studied subject more than three fourth (77.5%) of the studied subject were irregular in attending their colleges and 40% of them monthly absent from their college 5 days or more due to the impact of their chronic illness.

Table 2 Impact of Chronic Illness on College Attendance among the Studied Subject

Variables	Number (n=40)	%
College attendance:		
Regular	9	22.5
Irregular	31	77.5
Monthly absenteeism days:		
None	7	17.5
<5	9	22.5
5-	16	40.0
10-	6	15.0
15+	2	5.0

Table 3 represent clinical data of studied subject 70% of the studied subject suffer from bronchial asthma and half of them suffer from their chronic illness since birth with positive family history of chronic disease appear among 90% of them. The most common manifestations as revealed from this table was insomnia as reported by 80% of the studied subjects, digestion difficulty was reported by 75% and lack of socialization also were reports by 90% of them.

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Table 3 Clinical Data of the Studied Subject

Variables	Number (n=40)	%
1. Diagnosis:		
Bronchial asthma	28	70.0
Diabetes	3	7.5
Hypertension	9	22.5
2. Duration of illness:		
Since birth	20	50
<2	1	2.5
2-	6	15.0
4-	10	25.0
6-	3	7.5
3. Positive Family history of chronic illness.	36	90.0
4. Number of yearly hospitalization:		
<5	9	22.5
5-	10	25.0
10-	6	15.0
15-	5	12.5
20+	10	25.0
5. Chronic illness Manifestations:	N are not exclusive	
Weight problems.	12	30.0
Loss appetite.	11	27.5
Insomnia.	32	80.0
Mood change.	17	42.5
Walking problems.	8	20.0
Digestion difficulty.	30	75.0
Headache.	19	47.8
Drowsiness.	5	12.5
Joint pain.	26	65.0
Vision problems	8	20.0
Lack of concentration.	12	30.0
Allergy.	5	12.5
Lack of socialization.	5	90.0
Breathing difficulty.	16	40.0
Cough.	12	30.0
Running nose.	14	35.0
Others.	10	25.0

Table 4 represent distribution of studied subjects total score of knowledge about their chronic illness more than four fifth of them (82.5%) have very poor knowledge score regarding their chronic illness pre the program compared to none of them immediately post the program and only 15% after three months post the program with significant differences were found due to the impact of chronic disease self-management program.

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Table 4 Distribution of Studied Subjects Total Score of Knowledge

Total knowledge score	Before program		After program		At follow up		Z 1 P1	Z2 P2
	N	%	N	%	N	%		
Very poor	33	82.5	0	0.0	6	15.0	5.604	4.762
Poor	5	12.5	1	2.5	15	37.5	0.001*	0.001*
Average	1	2.5	10	25.0	16	40.0		
High	1	2.5	29	72.5	3	7.5		

** Significant*

Z1= comparison between before and after program Z2= comparison between before and at follow up. For each element of knowledge the score was categorized as very poor (if the study subject has <25% of knowledge), poor (if the study subject has 25-<50% of knowledge), average (if the study subject has 50-75%) and high (if the study subject has>75% of total score)

Table 5 represent distribution of studied subjects quality of life total score only one fourth of the studied subjects had high level of satisfaction toward their quality of life pre the program compared with 90% of them immediately post the program and 67.5% of them 3 months post the program with significant difference were found. Also in relation to importance of quality of life to them 72.5% had high importance compared to all of them immediately post and 90% three month post the program with significant difference were found.

Table 5 Distribution of Studied Subject's Quality of Life Index

quality of life	Before program		After Program		At follow up		Z 1 P1	Z2 P2
	N	%	N	%	N	%		
Satisfaction:							4.004	4.384
Poor(1-67)	15	37.5	2	5.0	0	0.0	0.001*	0.001*
Average(68-136)	15	37.5	2	5.0	13	32.5		
High(137-204)	10	25.0	36	90.0	27	67.5		
Importance:							3.071	2.428
Poor(1-67)	3	7.5	0	0.0	0	0.0	0.002*	0.015*
Average(68-136)	8	20.0	0	0.0	4	10.0		
High(137-204)	29	72.5	40	100.0	36	90.0		

** Significant*

Z1= comparison between before and after program Z2= comparison between before and at follow up.

Table 6 reflect distribution of studied subjects wellbeing level 7.5% of the studied subjects had high level of physical wellbeing , pre the program 5% had high level of psychological wellbeing , 37.5% had high level of spiritual wellbeing and 30% had high level of mental wellbeing compared with 95%, 42.5%,80%and 95% immediately post the program for the above items respectively with significant difference were found and 42.5%, 60%, 85% and 55% 3months post the program for the above items respectively with significant difference were found. The above results reflect that the chronic disease self-management program had a great impact on study subject's wellbeing level.

Table 6 Distribution of Studied Subject's Wellbeing Level

Wellbeing aspects	Before program		After program		At follow up		Z 1 P1	Z2 P2
	N	%	N	%	N	%		
Physical:							4.998	4.735
• Poor(1-13)	12	30.0	1	2.5	0	0.0	0.001*	0.001*
• Average(14-27)	25	62.5	1	2.5	23	57.5		
• High(28-40)	3	7.5	38	95.0	17	42.5		
Social:							4.082	0.905
• Average(14-27)	28	70.0	8	20.0	25	62.5	0.001*	0.366
• High(28-40)	12	30.0	32	80.0	15	37.5		
Psychological:							4.716	4.973
• Poor(1-13)	8	20.0	0	0.0	0	0.0	0.001*	0.001*
• Average(14-27)	30	75.0	17	42.5	16	40.0		
• High(28-40)	2	5.0	23	57.5	24	60.0		
Spiritual:							3.674	4.264
• Poor(1-13)	1	2.5	0	0.0	0	0.0	0.001*	0.001*
• Average(14-27)	24	60.0	8	20.0	6	15.0		
• High(28-40)	15	37.5	32	80.0	34	85.0		
Mental:							4.576	2.995
• Poor(1-13)	5	12.5	0	0.0	0	0.0	0.001*	0.003*
• Average(14-27)	23	57.5	2	5.0	18	45.0		
• High(28-40)	12	30.0	38	95.0	22	55.0		

* *Significant*

Z1= comparison between before and after program Z2= comparison between before and at follow up.

DISCUSSIONS:

Chronic disease self-management program has been shown to help participant to improve health care behaviors, health outcomes and reduce health care utilization.[21] it seek to empower them to deal with the disease and live better quality of life with fewer restriction from their illness. There is a strong evidence base that chronic disease self-management program is a core component of integrated chronic disease management.[22] This study aimed to assess effects of chronic disease self-management program on quality of life and wellbeing among chronic ill adolescents at Majmaah university female colleges.

The results of the present study revealed that more than half of the studied subjects were from education College, aged 17->19 years and had working father. About more than two thirds of the studied subjects diagnosed as bronchial asthma, complain from insomnia, digestion difficulties, lack of socialization and were irregular in college attendance due to the impact of their chronic illness. The current study subjects total score of knowledge were significantly improved after the program and at the follow up so the first research question was accepted; this finding agree with Johnston et. al., in 2008[22] whom mentioned that self-management program has been shown to be the most effective strategy at improving outcomes across wide range of the disease and improve patient knowledge about the condition. Also Velez in 1992,[23] support the importance of improving patients' knowledge through education and the associated benefits of improving compliance with health care appointments.

From the current study results there was significant difference in quality of life, level of satisfaction and importance post the program and at follow up so the second research question were accepted, this finding corresponding with Lorig et. al., in 2001a[24] whom found after 1 year of chronic disease self-management program the participant had improvement in energy, health status, social and role

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activities and self –efficiency. Also this finding agree with Lorig, et al in 2001[25] whom mentioned; there is strong evidence across studies that Chronic Disease Self - Management Program has a beneficial effect on physical & emotional outcomes, and health related quality of life. Also Smith, et. al., in 2013[26] mentioned that; the study findings indicate health-related quality of life improvements can be sustained months after the conclusion of CDSMP. This study finding supported by Russell, et al in 2009[27] whom mentioned comprehensive chronic disease self-management programs are innovative approaches to improve chronic illness care, quality of life and outcomes

From the current study results there was significant improvement in wellbeing Level among the studied subjects post the intervention with significant differences was found so the third research question were accepted this finding agree with Newman, et al., in 2004[28] whom mentioned that many individuals recruited in self-management program might show little evidence of depressed mood or increase anxiety also Johnston et. al., in 2008[22] added that self-management intervention have been shown to increase self-efficiency even in culturally diverse populations. Also Lorig et. al., in 2001a[24] concluded that chronic disease self-management program had been improved chronic patient health behaviors and health status which resulted in fewer hospitalizations and days of hospitalization and added we found that patient use of CDSMP was associated with better outcomes in all study domains—small but statistically significant improvements in health status, health behavior, self-efficacy, wellbeing and less use of the emergency department.

Cook, et. al., in 2009[29] reported that; pre- and post-intervention scores revealed significant improvement in self-reported symptoms, recovery, hopefulness, self-advocacy, and physical health; empowerment decreased significantly and no significant changes were observed in social support. The study subjects whom attending six or more sessions in chronic disease self- management program showed greater improvement than those attending fewer sessions in the program. Lorig et al., in 1999[30] mentioned that treatment subjects whom attended chronic disease self-management program when compared with control subjects, demonstrated improvements after 6 months in weekly minutes of exercise, frequency of cognitive symptom management, communication with physicians, self-reported health, health distress, fatigue, disability, and social/ role activities limitations. They also had fewer hospitalizations rate and days stayed in the hospital. Also Forjuoh et. al., in 2014[31] observed that chronic disease self-management program (CDSMP) has been found to be highly effective in improving general health statues and lowering hospitalization rates among studied subjects.

STUDY LIMITATIONS:

Study sample only 40 chronic ill adolescent whom appreciate to participate in the study.

CONCLUSION:

From the present study results it was concluded that chronic disease self-management program had improve study subjects total score level of knowledge, quality of life and well-being level with significant differences were found post the program.

RECOMMENDATIONS

From the current study results it was recommended that chronic disease self-management program demonstrated for large group of chronic ill adolescent for one year at least to manifest its impact on their adaptation with the chronic illness, life style modifications, health outcomes, quality of life and well-being level.

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