Middle East Journal of Nursing

June 2018
VOLUME 12 ISSUE 2

ISSN 1834-8742

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In the second issue this year we have two important papers from Saudi Arabia in the field of nursing.

Elbasuony M.M.M et al explored the undergraduate nursing students' perceived knowledge, attitude and usage of E-learning and blackboard learning system. They conducted a descriptive study during second semester, academic year 2016/2017, at Nursing Department, College of Applied Medical Sciences for Girls, Tehama, King Khalid University, Saudi Arabia. Convenient sample of 80 students were the study sample. Electronic questionnaire consisted of four parts: General basic information, 30 perceived knowledge questions on computer basics, e -learning and blackboard; 15 perceived Attitude items towards E- Learning and blackboard, and 27 items about students' usage of Computer, blackboard & E-learning Systems were used for data collection. Students' mean age was 20.8 and 66% of students were using computer for educational purpose. The results shown that 74% of students had average perceived knowledge about e-learning and black board, 75% of students' usage on e-learning and black board features was unsatisfactory and 44% of the students were having neutral attitude towards black board and E- Learning. There are statistically significant correlation between perceived knowledge and attitude towards e-learning and black board. The study findings reflected that nursing students perceived substantial knowledge and attitude towards e-learning and blackboard system that e-learning is highly valued by the students in their learning environment. Although, e-learning is widely accepted in institutions of Saudi Arabia, there is a need for the provision of appropriate training at different levels with experts regarding e-learning and blackboard system.

Alhelih, E.M et al did a secondary analysis of reported symptoms experienced by Saudi children and adolescents with cancer over multiple cycles of chemotherapy treatment, identifying experiencing similar symptom trajectories. The study involved 130 Saudi children and adolescents recruited from four tertiary hospitals who completed the sociodemographic and clinical data sheet, Memorial Symptom Assessment Scale (MSAS 10-18) and Karnofsky Performance Status (KPS) Scale. The authors found four discrete classes using latent class profile analysis were recognized: minimum distress (Class I), physical prominent distress (Class II), psychological prominent distress (Class III), and maximum distress (Class VI). Vomiting (M=0.88) was reported as the most distressing symptom in Class I, whereas lack of energy was the most prevalent distressing symptom in Class II (M=3.1). Subjects reported worrying (M=2.68) as the most distressing symptom in Class III of clustering, while lack of energy (M= 4.85) was reported to be the most prevalent in Class VI. They concluded that understanding antecedents and patterns of symptom trajectories may help practitioners to improve patients care more efficiently, permitting for refining patient outcomes and inspiring a reduction in health care costs and utilization.

In our CNE section we introduce a new case for the Palliative Care Nurse on:

Pain Management and Depression in a Palliative Care Patient.

UNDERGRADUATE NURSING STUDENTS' PERCEPTION AND USAGE OF E-LEARNING AND BLACKBOARD LEARNING SYSTEM

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Received: April 19, 2018; Accepted: May 10, 2018; Published: June 1, 2018
Citation: Mona Mohamed Megahed Elbasuony, Priya Gangadharan, Janula R., Shylaja J., Fatima Adam Gaber. Undergraduate nursing students' perception and usage of E-learning and blackboard learning system. Middle East Journal of Nursing 2018; 12(2): 3-13. DOI: 10.5742/MEJN.2018.93394

Abstract

Background: E-Learning is a computer based educational tool that can be delivered anytime and anywhere. It is rapidly increasing in nursing education and enables students to engage in exciting ways of learning through collaboration and serves to develop and implement technology that improves every aspect of education. Objective: to explore the undergraduate nursing students' perceived knowledge, attitude and usage of E-learning and Blackboard learning systems.

Methods: A descriptive study was conducted during the second semester, academic year 2016/2017, at Nursing Department, College of Applied Medical Sciences for Girls, Tehama, King Khalid University, Saudi Arabia. Convenient sample of 80 students were the study sample. Electronic questionnaire consisted of four parts: General basic information, 30 perceived knowledge questions on computer basics, e-learning and Blackboard, 15 perceived Attitude items towards E- Learning and Blackboard, and 27 items about students' usage of Computer, Blackboard & E-learning Systems, were used for data collection.

Results: Students' mean age was 20.8 and 66% of students were using a computer for educational purposes. The results show that 74% of students had average perceived knowledge about e-learning and Blackboard, 75% of students' usage of e-learning and Blackboard features was unsatisfactory and 44% of the students had a neutral attitude towards Blackboard and E- Learning. There was a statistically significant correlation between perceived knowledge and attitude towards e-learning and Blackboard.

Conclusion: The study findings reflected that nursing students perceived substantial knowledge and attitude towards e-learning and Blackboard system that e-learning is highly valued by the students in their learning environment. Although, e-learning is widely accepted in institutions of Saudi Arabia, there is a need for the provision of appropriate training at different levels with experts regarding e-learning and Blackboard system.

Key words: E-Learning, Nursing Students, perception, Blackboard learning system

Introduction

The term "e-learning" has been thrown around quite a lot in recent years. In essence, e-learning is a computer based educational tool or system that enables you to learn anywhere and at any time. Today e-learning is mostly delivered though the internet, although in the past it was delivered using a blend of computer-based methods like CD-ROM. (1) Over the past decade the structure of higher educational institutions has changed, partly due to the introduction of technological initiatives.(2)

E-Learning is now facilitating a more flexible learning approach; contemporary institutional structures are less robust than in previous years.(3) The structure of today's universities must be 'changeable' in order to integrate distance learning courses, and those institutions that will not or cannot change their structure to incorporate this technology may be bypassed by other educational providers. (4)

E-Learning offers online instruction that can be delivered anytime and anywhere through a wide range of electronic learning solutions such as Web-based courseware, online discussion groups, live virtual classes, video and audio streaming, Web chat, online simulations, and virtual mentoring.(5)

Globally, e-learning has been introduced to nursing curricula in a number of Western countries including Australia, Canada, Greece, Ireland, New Zealand, United Kingdom and America. The use of e-learning is rapidly increasing in nursing education.(6) E-Learning engages nurses by building interest and motivation while providing opportunities for active participation and protecting organizational interests with documented training. However, optimal success comes from consistent engagement. The fast-evolving nature of the nursing role and the requirements of registration bodies requires continuing professional development and lifelong learning in all nurses.(7) E-learning uses technology and services to provide training or learning material including tutorials, simulations, case-based, and game-based, learning modules.(8)

With the widening of Saudi's internet services, online learning or web-based instruction became practical. Moreover, an increased demand for higher education and a considerable shortage of female faculty led the Ministry of Higher Education to explore online learning approaches. (9) There are different types of Web Based Learning systems including, Computer-Mediated Communication (CMC), Web Course Tools (WebCT) and Blackboard (Bb).(10)

The Blackboard Learning System enables instructors to create and manage course matter, employ publisher content, communicate with students, and evaluate performance. Blackboard can be accessed from the internet at anytime and anywhere. (11) It has many features accessible to instructors and students including course documents, syllabus, hyperlinks and grade book. Moreover, it improves communication through announcements, discussions, virtual classroom and email. (12)

Bb enables students to engage in exciting ways of learning through collaboration and serves to develop and implement technology that improves every aspect of education. This reformed education system is a biggest challenge in nursing education. (13) The Blackboard system is regarded as a kind of e-learning. It is an online application to manage teaching and learning processes. It was designed to help and support both teachers and students to interact in the virtual classes and to learn using the electronic materials online as a kind of integration for the given activities and material face to face on campus classes. (14)

For the past few years integrated and reformed curriculum has been applied in the College of Applied Medical Science for Females, Tehama branch, King Khalid University with different innovative instructional methods to facilitate students' learning in the era of new trends in nursing education. Therefore, Bb as a learning system was an important inclusion in the reformed curriculum. Bb training has been given to the students and faculty at the beginning of the academic session. Also, students were frequently instructed to visit the Bb system as study materials are uploaded in the system. This study aimed to explore the undergraduate nursing students' perceived knowledge, attitude and usage of E-learning and Blackboard learning system.

Subject and Method

Research design: Descriptive study design was conducted during second semester, academic year 2016/2017.

Study setting: The Study was conducted at Nursing Department, College of Applied Medical Sciences for Girls, Tehama, King Khalid University, Saudi Arabia.

Study subjects: The total number of students in the nursing program was 232. By using convenient sampling technique, 80 students were selected from different study levels (level one to level eight) who were willing to participate in this study.

Tools of data collection: The tool for assessing perception and usage has been developed in English and it was translated into Arabic language by the researchers. The prepared tool has been validated by the experts in the same field. The tool for measuring attitude was adopted for the study, which was developed by Liaw, Huang & Chen.

The Electronic questionnaire consists of the following parts:

Part 1: It consists of General basic information about the students such as age, study level, GPA, computer courses taken, personal computer facility, internet facility at home, purpose of computer usage, social network community account, usage of web services or mobile applications for learning.

Part 2: It contains 30 questions, regarding perceived knowledge on computer basics, e-learning and Blackboard. It has three sections and each section consists of 10 questions.

Scoring: Right and wrong answers are scored one and zero respectively. The total score ranges from 0-30. Total scores were classified as follows, poor ranged from 0-9, Average ranged from 10-19 and Good ranged from 20-30.

Part 3: This part measures the perceived Attitude towards E- Learning and Blackboard which was created by Liaw, Huang & Chen 2007 (15), and used for this research. It includes 15 statements with a 5 points Likert scale from "strongly disagree" to "strongly agree. It was represented under four subsections such as E-learning as a self-paced learning environment (6 items), E-learning as an effective learning environment (3 items), E- learning as a multimedia environment (3 items), and teachers as an instructor – learning environment (3 items). The total score ranges from 15 - 75. Total scores were classified as follows, Negative attitude 15 – 35, Neutral attitude 36 – 55, Positive attitude 56 - 75.

Part 4: This part displays students' usage of Computer, Blackboard & E-learning Systems. It consists of 27 items grouped into 2 subsections, and these items were measured on a 6 point scale. The subsections are: usage of Blackboard & E learning tools which contain 7 items ranging from every day, few times a week, few times a month, once a month, never and don't know. Use of Computer and Social media contains 20 items ranging from Excellent, Very good, good, fair, poor, Don't know. Scores were classified to determine level of students' practices as follows; less than 60% indicates unsatisfactory practice and 60% or more indicates satisfactory practice.

Data collection procedure:

Data collection was done by using Google form (Electronic questionnaire) from all the selected samples. Each student was instructed to give the response individually.

Ethical consideration:

- Official permission with written letter clarifying purpose of the study was obtained from the college research ethical committee to conduct the field work of the study.

- The researchers explained the aim of the study to all participants included in the study and assured them about maintaining anonymity and confidentiality of the data.

Statistical method for analysis:

The present study data were grouped and analyzed using Microsoft excel. The descriptive statistics were applied and expressed in the form of frequencies, percentages and mean. The relation between the study variables such as perceived knowledge, attitude and usage were analyzed using correlation test (r). An association between demographic variables and study variables were assessed using ($\chi 2$) chi square test. The level of significance was considered at $p<0.05$. The analyzed findings are presented in tables and figures (next page).

Results

Table 1: Demographic Characteristics of the students (n= 80)

S. No	Items	Mean Value	
1.	Age in Years	20.8	
2.	Grade Performance Average (GPA)	2.96	
S. No	Items	Number of Students	Percentage %
3.	Computer Training course Taken		
	Yes	42	53
	No	38	47
4.	Personal computer facility (desktop or Laptop)		
	Yes	74	93
	No	6	7
5.	Internet facility at home		
	Yes	75	94
	No	5	6
6.	Duration of Computer usage		
	< 3 years	21	26
	3 – 5 years	28	35
	5 – 10 years	14	18
	> 10 years	17	21
7.	Student Academic level		
	Level 1	19	24
	Level 2	4	5
	Level 3	3	4
	Level 4	23	29
	Level 5	6	7
	Level 6	13	16
	Level 7	9	11
	Level 8	3	4

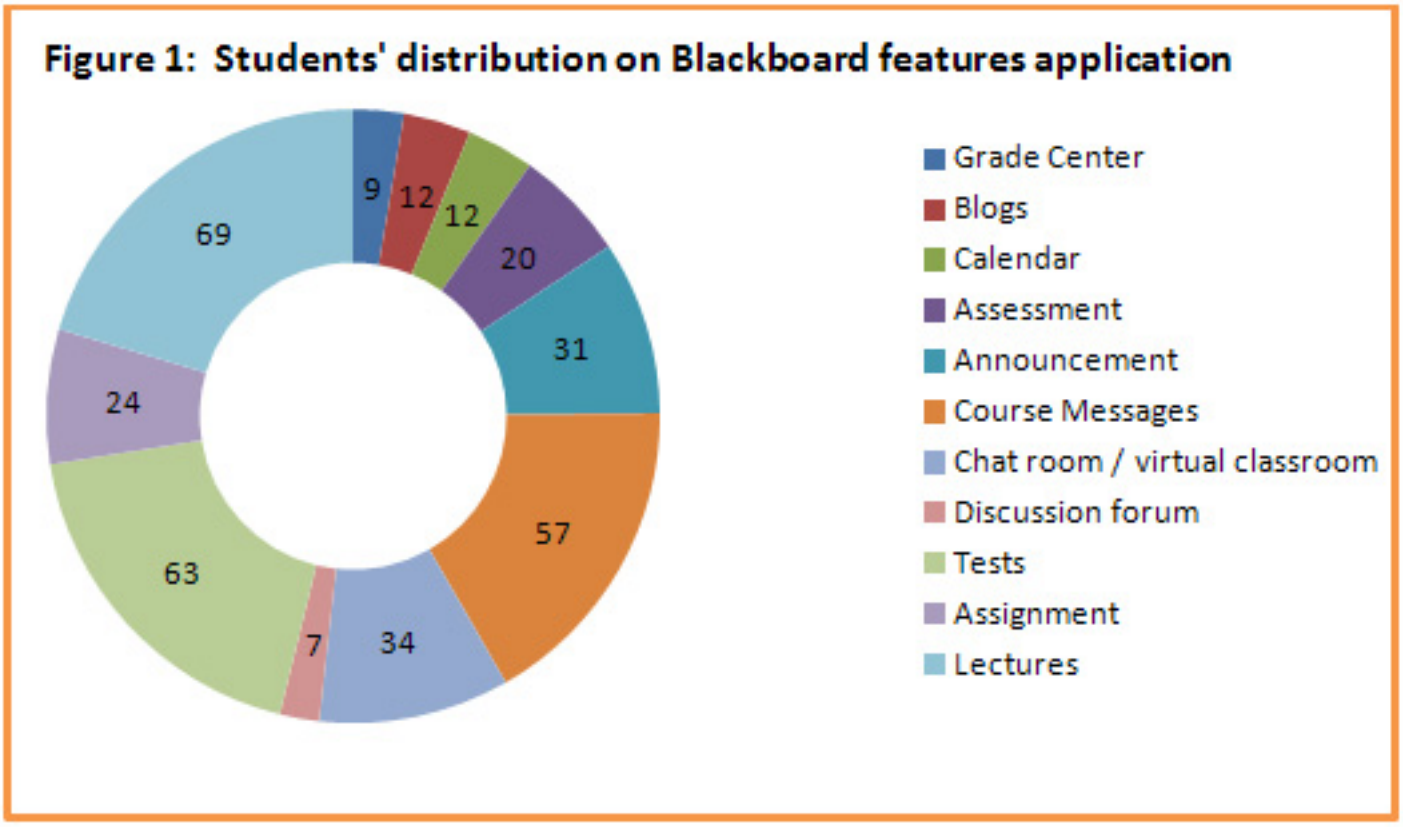
This table shows that the majority (29%) of study subjects belong to level 4 and most (24%) of the students belong to age group 21 years. More than half of the students (53%) were already taking computer courses. Almost an equal number of students have personal computer and internet facility 93%, 94% respectively. Also 35% of the students have been using a computer for 3-5 years.

Table 2: Base Line Information about Computer and E learning (n= 80)

S. No	Items	Number of Students	Percentage %
1.	Purpose of Computer Usage		
	Education	53	66
	Entertainment	9	11
	Communication	8	10
	All	16	20
2.	Social Network Member		
	Facebook	14	18
	Twitter	54	67
	You tube	48	60
	Instagram	62	77
	Linkendin	2	3
	Flikr	1	1
	Pin Interest	2	3
	Tumlr	0	0
	Bebo	2	3
	MySpace	1	1
	Google Plus	27	34
3.	Web services used for learning		
	Facebook	2	3
	Wikipedia	37	46
	YouTube	65	81
	Google app	29	36
	Whats app	49	61
	Search Engine	30	37
	Google Translate	56	70

This table infers that the majority (66%) were using a computer for educational purpose and 77% of the study subjects were in Instagram social network and the web services usage for learning especially; 81% were accessing You Tube.

Figure 1: This chart shows that the majority (69) of students were accessing Lectures, and subsequently test (63) and third majority (57) were availing course messages while very few students (7) were using a discussion forum.



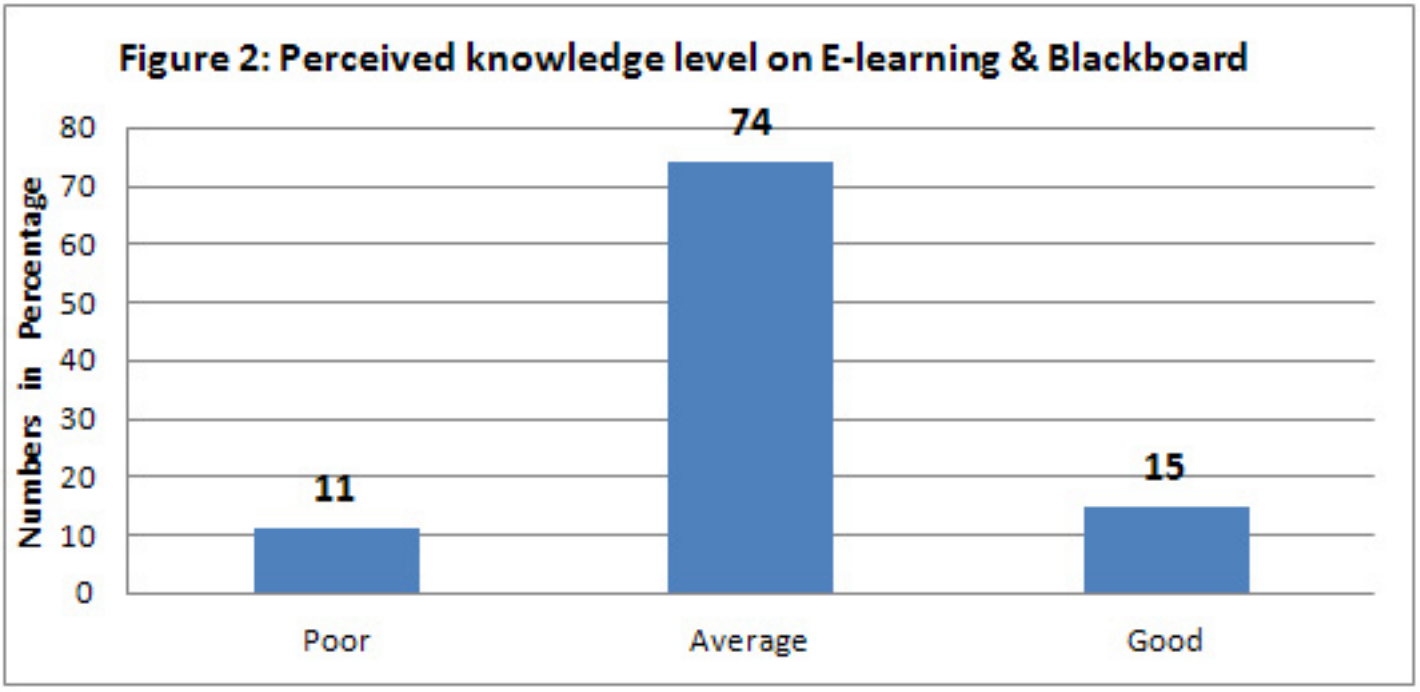


Figure 2: This diagram depicts that the majority (74%) of students had average perceived knowledge about e-learning and Blackboard and only 11% had poor knowledge.

Figure 3: This picture indicates that the majority of students (72%) had average perceived knowledge on E-Learning and 64% had average level on basic computer and also 40 % had a good level on Blackboard applications.

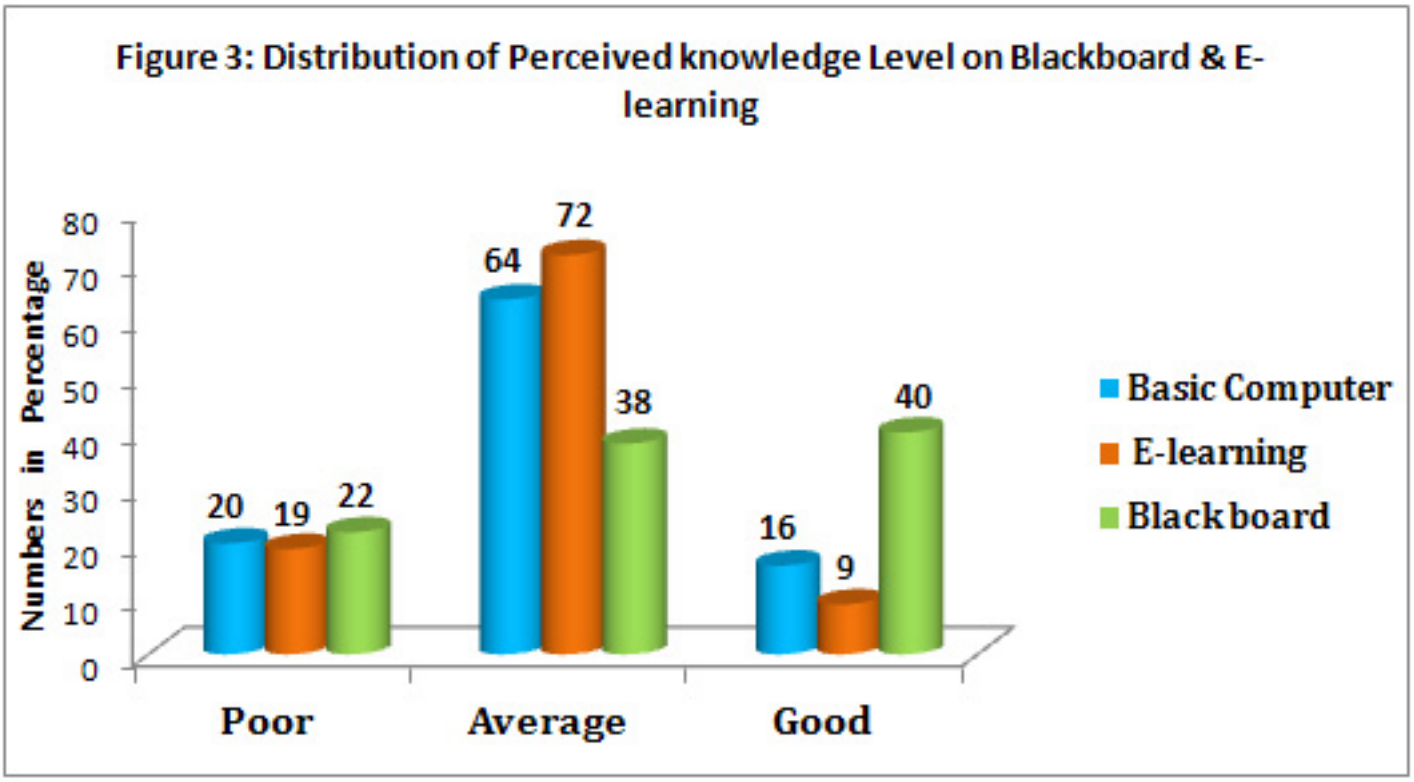


Figure 4: The majority of the students' usage on e-learning and Blackboard features were unsatisfactory level (75%) and the rest of the students' usage were satisfactory level (25%)

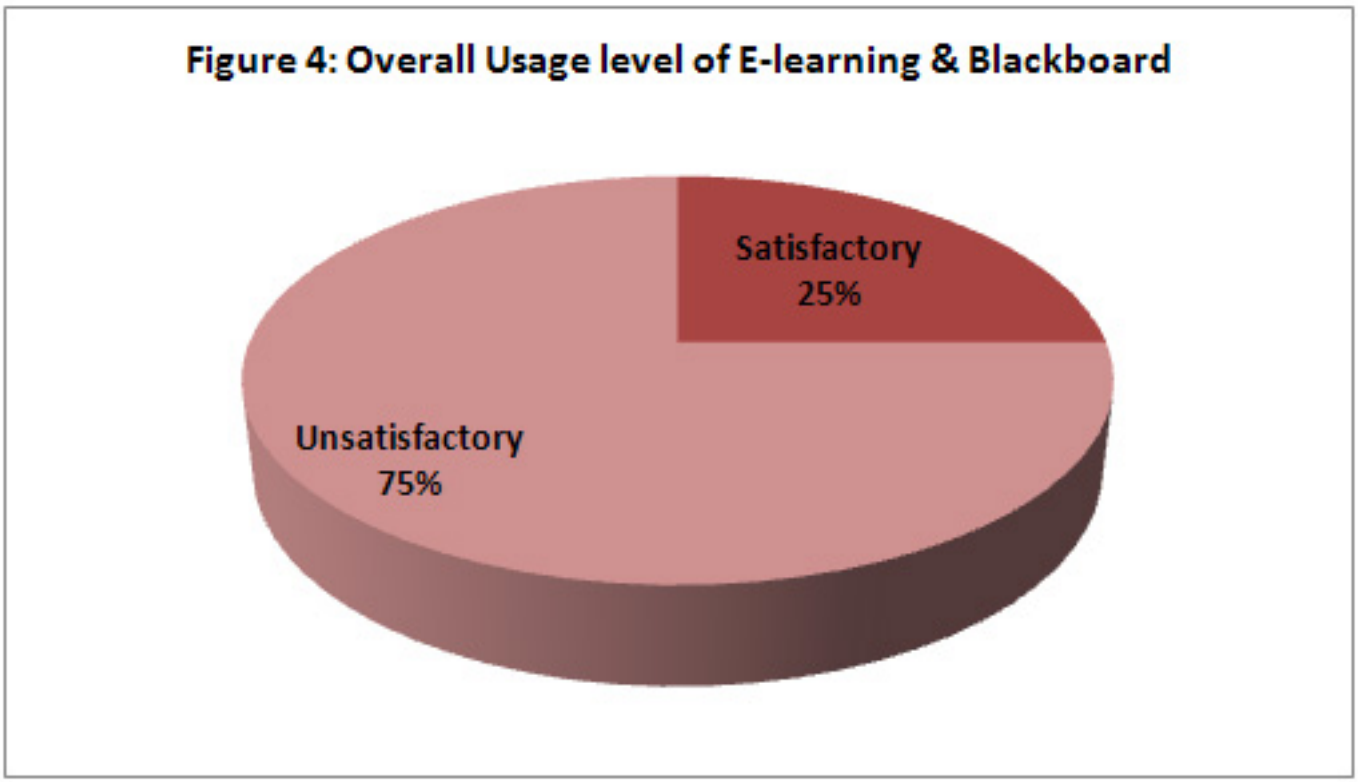


Figure 5: This diagram implies that the majority (44%) of the students had a neutral attitude and only 22% had a negative attitude towards Blackboard and E- Learning.

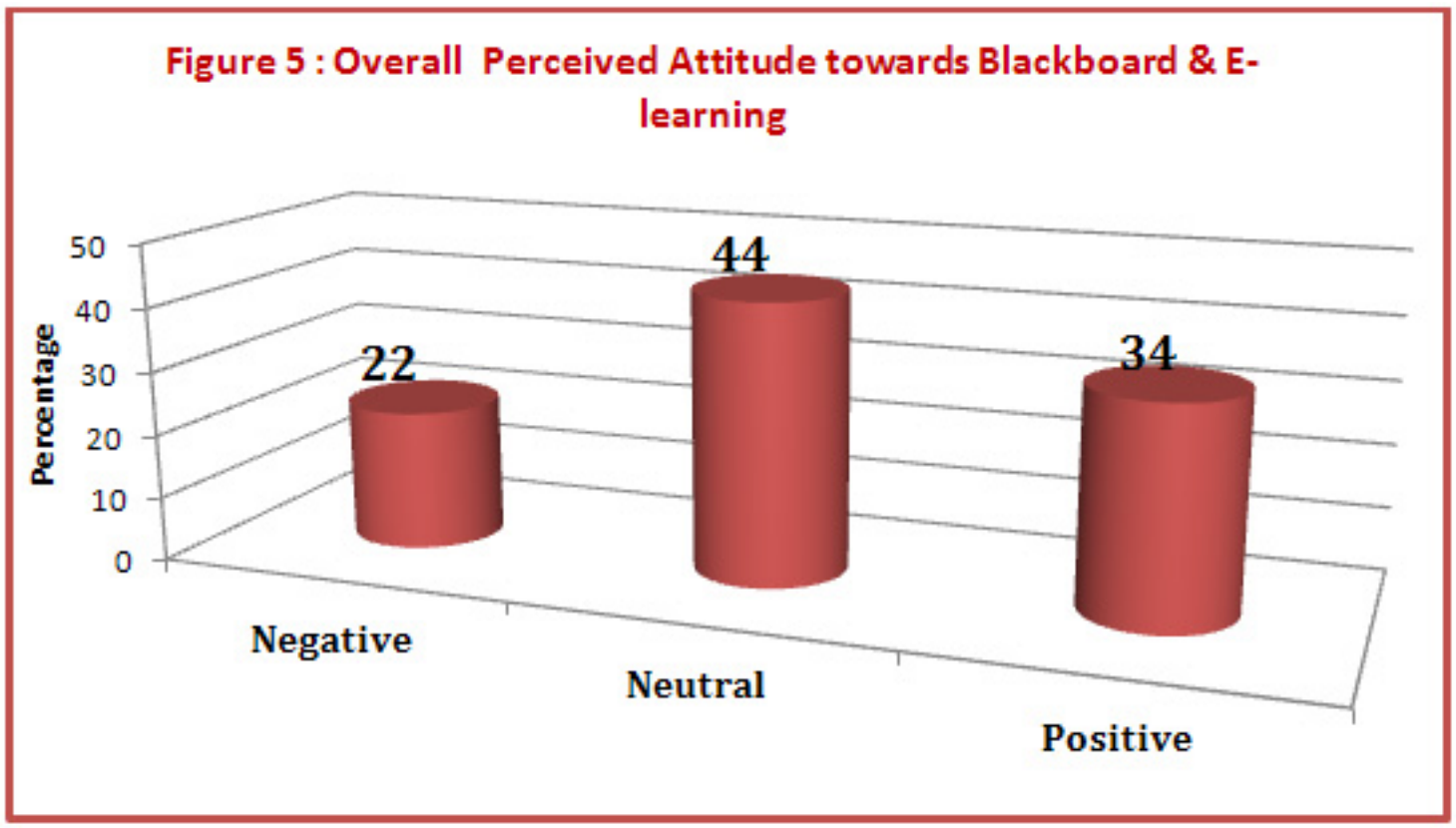


Figure 6: This figure shows that 38% of the students perceived had a noticeably high level of positive attitude towards multimedia instruction learning environment and 47% had a neutral attitude and only 20% rated a negative attitude on self-paced learning environment.

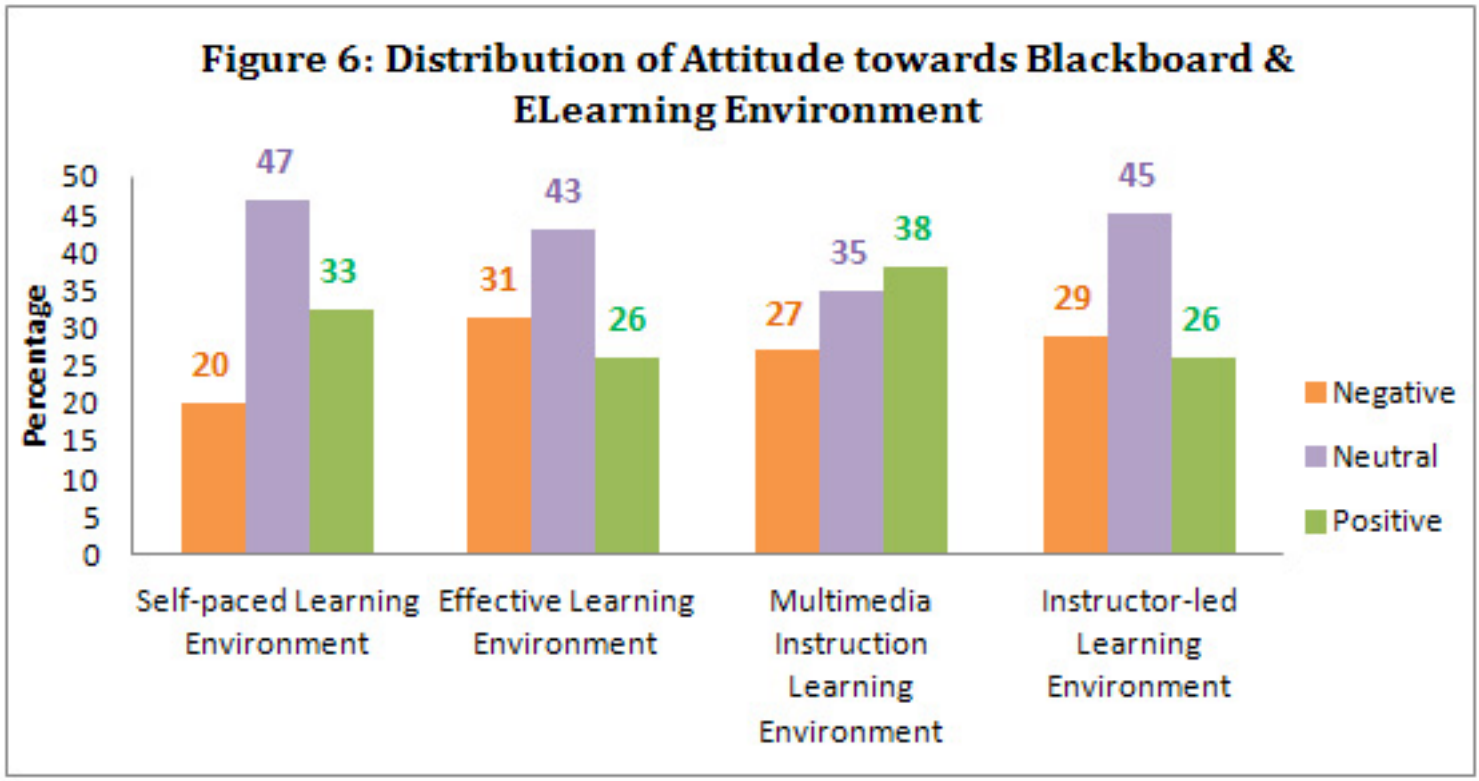


Table 3: Correlation between students perceived knowledge, attitude and usage

Correlation	Perceived Knowledge	Usage	Perceived Attitude
Perceived Knowledge			
Usage	0.0394 0.7265		
Perceived Attitude	0.3702 0.0006*	-0.0831 0.4607	

Cell contents: Pearson correlation **Significant at 0.05 level* *P- Value*

This matrix depicts that the correlation between perceived knowledge and attitude towards e-learning and Blackboard was statistically significant.

Discussion

The present study examined the Nursing students' perception and usage of E-learning and Blackboard learning system in their academic performance. Structured electronic questionnaire was used for data collection.

In the recent scenario most of the educational institutions are using advanced technologies to upgrade the knowledge of students. As the technology develops, the students are using their personal computers to update their knowledge and skills. The present study revealed that most of the students had prior knowledge about the use of computers. The use of computer skills are essential to have successful e-learning.(16) It is evident from the present study, the students were using their personal computers with internet access for learning. Roblyer (2003) (17) said that personal computers will provide a richer learning environment where the learner can be more actively involved in his or her own learning.

Ramirex (2003) (18) carried out a study about the impact of Internet on reading practices of College students in the National University of Mexico. The findings of the current study also revealed that there was a growing interest in digital reading. 94% of the study participants had an internet facility in their home and the majority of students were using the computers for their education purpose.

Vishranti Raut (2016) (19) stated that use of social media has been swiftly increasing during the last few years. It is not only being used for entertainment purpose but also there is heavy rise in the use of social media for education by the students. The respondents of the current study also stated that they were more interested in social media. It was more apparent that from the last decades social medias is helping to enhance knowledge.

YouTube video tutorials are considered highly effective tools in learning skills. (20) It was believed that YouTube is an effective tool in teaching computer skills and in cognitive achievement. (21) So the computer and internet are helping the students gain additional knowledge apart from their traditional learning. The present study also revealed that the students were using You Tube and other kinds of social networks such as Facebook, Twitter and Instagram with high interest.

Talal (2016) (14) said that the Blackboard system is regarded as a kind of e-learning. It is an online application to manage teaching and learning processes. It was designed to help and support both teachers and students to interact in the virtual classes and to learn using the electronic materials online. The findings of the present study revealed that the Blackboard system was used by the students to send and receive course messages, to take lectures made by the teachers, to have assignments for evaluation. A few students were using other applications of Blackboard system like announcement, Blogs, calendar, grade center and discussion forum also.

Perception level of E-learning & Blackboard

When discussing the Overall Perception level of E learning & Blackboard, the study reported that the vast number of participants had average perception in using E learning & Blackboard system. This finding supports the previous research done by Marilynne Coopasami (2017) (22) where the participants were not technologically ready to fulfill e-Learning requirements. So it was more apparent that the students need further assistance to use Blackboard and e-learning systems. As the University is giving sufficient significance to the Blackboard system the students had a good perception about the Blackboard system more than basic computer and e learning.

Level of usage towards E-learning & Blackboard

Based on a huge growth and challenge facing e-learning systems, using Blackboard as an online learning system is persisting among universities especially in Saudi Arabia.(23) So this study was also interested to know the usage level of e-learning and Blackboard system, and the results showed 25% of students only having satisfactory usage level of e-learning and Blackboard system. As it indicated the students need additional motivation to use e-learning systems.

Attitude towards E- learning & Blackboard

Visalam et al. (2015) (24) concluded with high confidence that university students are willing to accept many courses

via online mode. The findings of the present study showed that 34% of participants have a positive attitude towards e-learning and Blackboard. The present study assessed the student's attitude towards the following components: self-paced learning environment, effective learning environment, and instructor-led learning environment. Among the above said components the students had a good attitude towards multimedia instruction more than the others. Jesus Izquierdo et al.(25) examined the university learners' attitude towards multimedia instruction and stated that where there is combination of illustrations, diagrams, charts, maps, and photos, or dynamic graphics such as animation and video in learning tasks, there the students will get provoked to advance their language.

Correlation between Attitude, Usage and Perception of E - learning & Blackboard:

E-learning is widely accepted in higher education institutions. Achimugu et al. (2010) (26) suggested that the positive attitudes and the willingness of students will enhance them to engage in e-learning courses and suggest that there is a great potential for e-learning initiatives. The findings of the present study also stated that the perception is having a positive correlation with attitude of students towards E - learning and Blackboard.

Limitations

• This study included only female students. So gender differences cannot be identified.

• It is important to note that the findings presented in this article are based on a study from only one institution with limited number of participants, especially among nursing students.

Recommendations

• The authors of this study recommend to conduct this study with large group of students and with other disciplines or other universities.

• The study can be conducted in campus after enhancing sufficient technical support with adequate internet access.

• The study findings can be compared with other disciplines or other universities.

• More training programmes can be conducted by experts to improve usability of Blackboard and e-learning system among students.

Conclusion

The study results suggest that the nursing students perceived substantial knowledge and attitude towards e-learning and Blackboard system. It reveals that e-learning is highly valued by the students in their learning environment. Though, e-learning is widely accepted in institutions of Saudi Arabia, there is a need for the provision of appropriate training at different levels with experts regarding e-learning and the Blackboard system. Furthermore the study strongly recommends to apply E-learning and Blackboard system along with traditional methods of teaching.

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CANCER TREATMENT - RELATED SYMPTOMS AGGREGATION AND DISTRIBUTION AMONG SAUDI CHILDREN WITH CANCER

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Received: April 19, 2018; Accepted: May 10, 2018; Published: June 1, 2018
Citation: Eyad M. Alhelih, Omar G. Baker, Suzan Ali Almomani, Bashar Ghazi Baker. Cancer Treatment - Related Symptoms Aggregation and Distribution Among Saudi Children with Cancer; 12(2): 14-21. DOI: 10.5742/MEJN.2018.93393

Abstract

Purpose: **Children and adolescents with cancer experience multiple distressing symptoms during and after chemotherapy treatment. This study aimed at secondary analyzing of reported symptoms experienced by Saudi children and adolescents with cancer over multiple cycles of chemotherapy treatment, identifying the experiencing of similar symptom trajectories.**

Methods: **Subjects were 130 Saudi children and adolescents recruited from four tertiary hospitals who completed the sociodemographic and clinical data sheet, Memorial Symptom Assessment Scale (MSAS 10-18) and Karnofsky Performance Status (KPS) Scale.**

Findings: **Four discrete classes using latent class profile analysis were recognized: minimum distress (Class I), physical prominent distress (Class II), psychological prominent distress (Class III), and maximum distress (Class VI). Vomiting (M=0.88) was reported as the most distressing symptom in Class I, whereas lack of energy was the most prevalent distressing symptom in Class II (M=3.1). Subjects reported worrying (M=2.68) as the most distressing symptom in Class III of clustering, while lack of energy (M= 4.85) was reported to be the most prevalent in Class VI.**

Conclusion: **Understanding antecedents and patterns of symptom trajectories may help practitioners to improve patients' care more efficiently, permitting refining of patient outcomes and inspiring a reduction in health care costs and utilization.**

Key words: **Cancer treatment-related symptoms, symptom clusters, symptom trajectory, chemotherapy-induced symptoms, children with cancer, adolescents with cancer.**

Introduction

Regardless of cancer cytopathological features, it is well documented that children with cancer experience various upsetting symptoms related to disease process or treatment modality (Rodgers et al, 2013). Satisfactory relief of these distressing symptoms is an imperative goal for patients, parents and practitioners during treatment for cancer (Miller et al, 2011; Rodgers et al, 2016; Hovén et al, 2017). Not only are these upsetting symptoms key contributors to decreased perception of quality of life, disability to function and disease-related interference with daily activities, but they may also disturb treatment process and impact treatment efficacy (Arslan et al, 2013; Baggott et al, 2014). Proper and prompt assessment and management of disease-related or treatment-related symptoms decreases recurrent hospitalization, treatment cost, and patient suffering (Kestler and LoBiondo-Wood, 2012; Rodgers et al, 2016; Erdem & Toruner, 2018.).

Dodd, Miaskowski, and Paul (2001) were the pioneers when they authored the first paper on symptom clusters in cancer patients. In that study, they defined symptom cluster as, "three or more concurrent symptoms that are related to each other but are not required to have the same etiology" (p. 468). Four years later, Kim and colleagues (Kim, McGuire, Tulman, & Barsevick, 2005) revised this definition as follows: "two or more symptoms that are related to each other, occur together, composed of stable groups of symptoms, are independent of other clusters and may reveal specific underlying concepts of symptoms." (p. 278). Recently, (Miaskowski et al., 2017) recommended extra elements for symptom cluster definition, including: symptoms that may share a common outcome, the sequential features, and the patient's symptom experience, along with the phenotypic and molecular mechanisms allied with the categories of symptoms inside the symptom cluster.

To date, abundant published research on symptom clusters patterns in pediatric oncology has focused on the complexity of symptoms experienced by children and affirm the diversity and discrepancy in distress level across treatment phases (Docherty, 2003; Ruland et al, 2009; Kestler and LoBiondo-Wood, 2012; Baggott et al, 2010; Baggott et al, 2014; Rodgers et al, 2016; Erdem & Toruner, 2018). Despite the growing number of symptom trajectory research, no gold standards exist to determine the most fitting tool that could be used to assess symptom clusters; the optimum approaches used for symptom trajectories abstraction; the optimum symptom dimension(s) to use to generate the trajectory; or the utmost proper time to measure the experience of symptoms (e.g., explicit point during the running of cancer treatment protocols). Due to no existing gold standard; a great amount of variability is noticed in the methodologies used to assess symptom clusters in pediatric oncology patients.

The abundance of cancer literature supports a high occurrence of distressing symptoms during chemotherapy in children with different types of cancer. Such symptoms may include but are not limited to, fatigue, insomnia, pain, mood fluctuation, changes in appetite, nausea and vomiting. Studies have found that the prevalence of fatigue and pain in children treated with chemotherapy decreased over time while nausea persisted to stay the same during the hospitalization period for a group of children 10–17 years of age (Miller et al, 2011; Baggott et al, 2014; Rodgers et al, 2016). In a Turkish study 54 children and adolescents reported 4 to 5 symptom trajectories in the first three months following diagnosis and proved a wide range of emotional and physical symptoms (Atay et al, 2012).

A previous longitudinal study (Beijers et al, 2012) indicated that the occurrence of chemotherapy –induced symptoms has been reported to be around 75% in the first seven days after administering chemotherapy to children with cancer, and they are also prone to develop these symptoms more than adults in this period.

Yeh et al, (2008) used the Memorial Symptom Assessment Scale 10Y18 (MSAS 10-18) to evaluate symptom trajectories among a hundred and forty-four pediatric patients in Taiwan. Results revealed 5 trajectories during stages of chemotherapy treatment as well as after the end of the therapy. The identified 5 trajectories were: (1) symptoms attributed to respiratory and circulatory system malfunction; (2) symptoms attributed to sensory distress and body image; (3) eating difficulties and body image; (4) fatigue, insomnia, and depression and (5) symptoms attributed to GI irritations and discomfort.

Much of the symptom trajectory published papers have focused on using a variable – centered method, which focuses on associations among variables, such as multiple regression and correlation procedures, or on explorations of mean differences, such as analysis of variance (ANOVA). The variable-centered method though, limits generalization of results to subjects since the information attained by the statistical approaches is variable oriented, rather than being individual oriented (Bergman & Magusson, 1997).

Knowing how symptoms aggregate in Saudi children with cancer during chemotherapy treatment may provide understandings into consequences or outcomes of this disturbing disease. The current study will add to the body of knowledge of disease-related and treatment-related symptom trajectories in children with cancer in Saudi Arabia. Therefore, this study sought to secondary analyze patient-reported symptoms experienced by Saudi children and adolescents with cancer, over multiple cycles of chemotherapy treatment, identifying the experiencing of similar symptom trajectories.

Methods

Sample and study procedure

This study was a secondary analysis of data collected from a descriptive, longitudinal study that used a package of self-report surveys to attain data from a convenient sample of 132 Saudi children and adolescents who were 14 to 18 years old, able to read and write Arabic and who could sign consent or give assent to a form between February 2013 and June 2014. The purpose of the parent study which was conducted by the same authors was to describe changes in symptom trajectories of 31 symptoms among Saudi children and adolescents during receiving chemotherapy treatment in four tertiary hospitals in Saudi Arabia.

From the parent study 132 participants were identified as eligible to be recruited in this secondary analysis. 2 subjects were excluded from this secondary analysis because they were treated by concurrent radiotherapy. Thus, the total subjects for this analysis were 130.

The parent study used clinical and demographic data questionnaire as well as valid and reliable Arabic versions of Karnofsky Performance Status Scale (KPS) and the Memorial Symptom Assessment Scale (MSAS10-18). Both scales were introduced to the participants three times; the first time was immediately before the administration of the chemotherapy cycle and the other two times were after one and two weeks of receiving the therapy. Although the parent study was approved by Human Subject Review Board at each study site, the current secondary analysis was not considered a human subject research and thus did not need IRB approval.

Measures

Clinical and Demographic data were collected at baseline and included age, gender, time since diagnosis, medical diagnosis, number of relapses and setting of chemotherapy administration (in-patient or out-patient clinics).

Karnofsky Performance Status (KPS) Scale is commonly used in the literature to appraise functional status in patients with cancer and has well recognized reliability and validity (Karnofsky, 1977). Subjects appraised their functional status using the KPS scale that fluctuated from 30 (I feel severely disabled and need to be hospitalized) to 100 (I feel normal; I have no complaints or symptoms) (Ando et al., 2001; Schnadig et al., 2008).

The MSAS 10-18 is a self-report survey intended to evaluate the multidimensional experience of symptoms. Using the MSAS, subjects were asked to specify whether they had experienced each symptom in the previous seven days (i.e., occurrence of symptom). If they had experienced the symptom, subjects were asked to rate its severity of occurrence, frequency of occurrence, and distress. Severity of symptom was appraised using a four-point Likert scale (i.e., 1 = slight, 2 = moderate, 3 = severe, 4 = very severe). Distress of symptom was assessed using a five-point Likert scale (i.e. 0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4 = very much). The reliability and validity of the MSAS is well recognized in oncology studies (Portenoy et al., 1994a; Portenoy et al., 1994b).

Translation of the KPS and the MSAS 10-18 into Arabic was done in the parent study. The parent study strictly followed the model of Brislin et al (1973) and the procedures by Miller (2001). Pretesting of the Arabic language tools was completed with 7 children and adolescents with cancer; they found the tools easy to complete.

Data analysis

Statistical Package for the Social Sciences (SPSS, 2015), version 23.0, was used for data management and calculating descriptive statistics and frequency distributions for demographics and clinical characteristics. Alpha was set at 0.05 and no adjustments were made.

Cluster analysis was carried out using Stata version 13.0 (Stata Corp, 2013). The authors carried out Latent Class Profile Analysis (LCPA) using Mplus Version 7 (Muthen & Muthen, 1998-2012). Estimation was done using robust maximum-likelihood through the Expectation-Maximization (EM) algorithm (Muthen & Shedden, 1999). Latent classes optimal number was selected by the Akaike Information Criterion (AIC), Vuong-Lo-Mendell-Rubin (VLMR), Bayesian Information Criterion (BIC), Entropy, Boot Strapped Likelihood Ratio Test (BLRT) and the underlying substantive/ logical elucidation of the resulting classes.

Results

Clinical and demographic characteristics

The subjects mean age was 15.5 years, and ranged from 11 to 17.5 years. They were mainly Saudi (130, 100%), male (78, 60%), diagnosed with acute lymphoblastic leukemia (52, 40%) and receiving chemotherapy in the inpatient wards (104, 80%), predominantly having average KPS score of 81.0 (SD=16.2). Most subjects had less than one relapse (100, 76.9%). Table 1 presents the results.

Symptom Clusters Identification

The authors identified related symptoms from the MSAS 10-18, which evaluates the experience of symptoms among subjects for the previous 7 days. Amongst the scale's 31 items, seven symptoms (lack of energy, pain, nausea, vomiting, loss of appetite, feeling sad and worrying) showed increase in their occurrence and severity in the results of the parent study. Five symptoms referred to physical dimension (lack of energy, pain, nausea, vomiting, loss of appetite) and the two remaining symptoms referred to psychological dimension (feeling sad and worrying) were introduced in this secondary analysis as proxies for symptom clusters.

Table 1: Clinical and demographic characteristics (n=130)

Gender	
Male	78 (60%)
Female	52 (40%)
Age	
Mean (SD)	15.5 (2.3)
Range	11-17.5
Median	14.25
Diagnoses	
Acute lymphoblastic leukemia	52 (40%)
Acute myeloid leukemia	18 (13.8%)
Other leukemia	20 (15.4%)
Central nervous system tumors	12 (9.3%)
Hodgkin disease	10 (7.7%)
Non-Hodgkin lymphoma	9 (6.9%)
Other solid tumors	9 (6.9%)
Chemotherapy Administration Setting	
Inpatient	104 (80%)
Outpatient	26 (20%)
KPS	
Mean (SD)	81.0 (16.2)
Range	43-100
Median	88
Relapses	
0	100 (76.9%).
1	18 (13.8%)
2 or more	12 (9.3%)

Table 2: Data fit to LCPA

Class	Entropy	BIC	AIC	BLRT	VLMR
I	0.901	117,472.065	117,274.630	p< .001	p< .001
II	0.877	113,899.366	113,695.525	p< .001	p< .001
III	0.891	112,664.639	112,484.051	p< .001	p = .0078
VI	0.864	111,455.647	111,088.494	p< .001	p = .0823

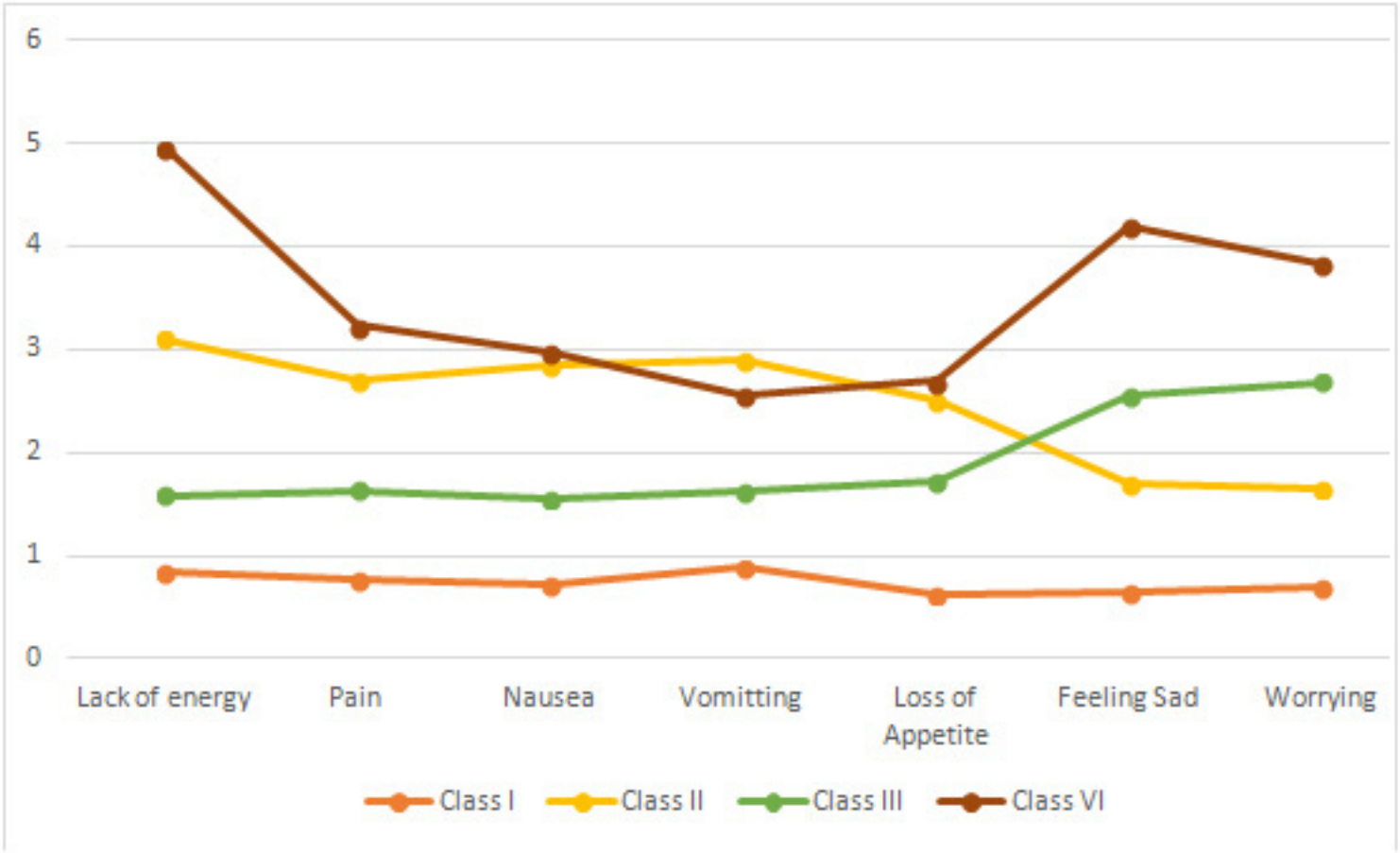
Through using Latent Class Profile Analysis (LCPA), Table (2) reveals that 4 discrete classes of symptom clustering were recognized (Classes I- VI). In order to simplify naming the resulted subgroups, the authors established numerical cut points to be compared with the latent classes of each symptom scores (mild < 1.5; moderate = 1.5-2.5; severe > 2.5). Latent classes were labeled based on the mean scores for MSAS 10-18 as presented in Table (3) and Figure (1). Class I (26.2%) was featured by slight levels of psychological (M = 0.67) and physical symptoms (M = 0.77) and was categorized "minimum distress." While class II (30.8%), named "physical prominent distress," was featured by a modest level of psychological symptoms (M = 1.67) but a severe level of physical symptoms (M = 2.81). Meanwhile, class III (20.0%), named "psychological prominent distress," was featured by a severe level of psychological symptoms (M = 2.615) but a modest level of physical symptoms (M = 1.62). Finally, Class VI (23%), named "maximum distress," was featured by severe levels of both psychological symptoms (M = 4.01) and physical symptoms(M = 3.282).

Table 3: Highest reported MSAS distressing symptom scores within the latent classes

	Class I	Class II	Class III	Class VI
Symptom	Minimum distress *n*=34; 26.2%	Physical prominent distress *n*=40; 30.8%	Psychological prominent distress *n*=26; 20%	Maximum distress *n*=30; 23%
Lack of energy	0.85	3.1	1.58	4.95
Pain	0.76	2.7	1.63	3.23
Nausea	0.72	2.85	1.55	2.98
Vomiting	0.88	2.9	1.62	2.56
Loss of appetite	0.63	2.5	1.72	2.69
Feeling sad	0.65	1.7	2.55	4.2
Worrying	0.69	1.56	2.68	3.83

$p < .001$

Figure 1: Highest reported distressing symptoms scores within the latent classes



Discussion

According to authors' best of knowledge this study is the pioneer to use LCPA model to detect symptom aggregation and distribution among Saudi children and adolescents treated with chemotherapy. According to the study results, classifying patients by classes of symptoms clustering could be more helpful clinically in comparison with addressing distinct symptoms, as it might permit practitioners to elucidate which class could be endangered by improper treatment consequences. It could also be helpful to advance strategies of symptom management for grouped and aggregated symptoms, which might be modified to treat a specific symptom profile.

The results of this study revealed four diverse classes of symptom clusters; subjects who experienced minimum distress (Class I), those who experienced physical prominent distress (Class II), subjects who experienced psychological prominent distress (Class III) and those who experienced maximum distress (Class VI). These findings were supported, somehow, by previously conducted studies (Ekti and Conk, 2008; Jager et al, 2008; Yeh et al , 2008; Yeh et al, 2009; Williams et al, 2014). Vomiting (M=0.88) was reported as the most distressing symptom in Class I, whereas lack of energy was the most prevalent distressing symptom in Class II (M=3.1). Subjects reported worrying (M=2.68) as the most distressing symptom in Class III of clustering, while lack of energy (M= 4.85) was reported to be the most prevalent in Class VI (Yeh et al , 2008; Yeh et al , 2009; Williams et al, 2014; Rodgers et al, 2016).

Distressing physical symptoms clustering in children with cancer were acknowledged by the findings of previous studies (Rodgers et al, 2016; Erdem & Toruner, 2018). Literature conveyed that physical symptoms should not be measured autonomously from psychological symptoms since both of them occur concurrently in children treated with chemotherapy (Rodgers et al, 2016). This paper acknowledged previous studies results by using MSAS 10-18, which is considered a valuable method for integrating both psychological and physical – related factors into symptom clustering.

Current study results confirmed that clustering of psychological symptoms was vague regardless of the measurement used. Whereas the pervasive nature of clustering of these symptoms approved previous findings of the high occurrence rates for feeling sad (Erdem & Toruner, 2018) and worrying (Yeh et al , 2008; Yeh et al , 2009; Williams et al, 2014; Rodgers et al, 2016) in children undergoing cancer chemotherapy treatment. Patterns of clustering of physically distressing symptoms; lack of energy pain, nausea, loss of appetite and vomiting were consistent with earlier studies (Ekti and Conk, 2008; Jager et al, 2008; Yeh et al , 2009; Baggott et al, 2012; Williams et al, 2014; Rodgers et al, 2016).

Quite a few limitations of this study must be acknowledged; using secondary analysis of data may limit the ability to evaluate other important factors to determine groups of clusters. Another limitation recounts to the restricted number of symptoms being evaluated, which might not signify the multifaceted group of symptoms that children with cancer experience. Particularly, two psychological and five physical symptoms were assessed. Small heterogenous sample size (n=130) might affect assessment of symptom aggregation patterns over time.

In spite of limitations, this study findings validated the practicality of LCPA for determination of symptom clusters that may offer information to lead proper management of cancer patients clinically. Additional research is required to assess all possible predictors of numerous symptoms.

In conclusion, no known study recognized the benefits of interventions targeted toward various symptoms in cancer treatment. Treating one symptom may indirectly impact another symptom in the trajectory. For instance, approaches to improve sleep pattern by enhancing pain management could lead to reducing fatigue.

The main findings of this study may have implications for nursing clinical practice. The results verified the interdependence of all dimensions of symptoms clustering, representing that psychological and physical symptoms are not independent in cancer. Yet, practitioners and patients habitually focus more on recognizing physical, more willingly than psychological symptoms.

Conclusion

Understanding antecedents and patterns of symptom trajectories may help practitioners to improve patients' care more efficiently, permitting for refining patient outcomes and inspiring a reduction in health care costs and utilization. The method converging on symptom trajectories is also possible to produce clinically valuable understandings that might lead to the expansion of innovative symptom management protocols. Practitioners could target explicit upsetting symptoms confined within a trajectory to decrease total symptom profile, which will yield decrease of health care cost, mortality and disease-specific morbidity. Furthermore, serving patients recognize how their symptoms group might encourage improved self-management. Patient and practitioner teaching might emphasize the monitoring of symptom grouping rather than separate symptoms and could boost symptom acknowledgement. Alertness of one symptom can prompt self-assessment for the existence of added symptoms if patients recognize that symptoms happen in clusters; responsiveness of further symptoms may enable sensible self-care and avoid costly hospital readmission for symptom management.

Acknowledgment

The authors would like to thank all the patients participated in the current study. The parent study was funded by SANAD Society for Cancer Children Support in Riyadh-Saudi Arabia.

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Case presentation

Ahmed is a 73 man, who was diagnosed with prostate cancer soon after marrying for the second time afetr his first wife died. He underwent a TURP and had localised radiotherapy to his prostate area. Ahmed has a past history of hypertension.

He and his second wife live in a semi rural area. They enjoy gardening and walking. Ahmed's first wife died of a cerebrovascular accident.

Four years after his original diagnosis of prostate cancer, Ahmed presents with moderately severe abdominal pain, which is fully investigated in hospital. A CT scan reveals secondaries in several pelvic lymph nodes. A bilateral orchidectomy is performed and he is referred to a radiation oncologist for review. Ahmed is put into your care as the local palliative care nurse and asks for a hom,e consultation. You discuss his feelings about the recurrence and give supportive counselling. Following your suggestion he attends a cancer support group.

Further History

A bone scan, PSA and ALP are ordered and the results are as follows:

Bone Scan: multiple sites of active disease in the spine, pelvis, ribs and proximal appendicular skeleton.

PSA: 75 (Normal < 4.0 ng/ml) ALP: 410 (Normal range 30-120 U/L)

The radiation oncologist informs Ahmed that his recent orchidectomy was unsuccessful as the bone scan revealed the cancer had spread to many bones throughout his body. Ahmed is shocked and very upset by this news. Although the specialist suggests that Ahmed consult a different oncologist with a view to commencing hormone treatment, Ahmed is left with the impression that nothing can really be done for his condition.

His wife, Fatima, telephones your surgery that day after Ahmed's consultation with the radiation oncologist. She requests a home visit for Ahmed. You find him very distressed after receiving the bad news about his disease progression. He is also weak and can hardly stand up. He tells you of increasing back pain over the previous three days which is exacerbated by lying down, coughing or straining. He asks you for an injection to "end it all".

Question 1: What can you now do for Ahmed?

Select one or more of the following

1. Immediately perform a physical examination to exclude spinal cord compression
2. Investigate the reasons behind his request to end it all
3. Arrange an urgent MRI
4. Commence oral dexamethasone
5. Prescribe an antidepressant
6. Arrange a lumbar spine X-ray
7. Arrange referral to a community based palliative care counselling service.

Answers to Question 1

Selection 1. Immediately perform a physical examination to exclude spinal cord compression

Answer:
The authors disagree.

Performing a physical examination in this situation is essential, however the request for an injection 'to end it all" needs to be explored in more detail first. If this request is ignored, the patient is likely to feel he is not being listened to.

Selection 2: Investigate the reasons behind his request to end it all.

Answer:

The authors agree.

It is important the request for an injection to 'end it all' be addressed. If this is ignored Ahmed will feel he is not being listened to. It is important to discover the reasons behind this request so they can be addressed. Being listened to and having his distressed feelings acknowledged may be sufficient to change his mind.

Selection 3: Arrange an urgent MRI

Answer:

The authors agree.

An MRI is the usual initial investigation for making a diagnosis of spinal cord compression.

Selection 4: Commence oral dexamethasone.

Answer:

The authors agree.

Oral dexamethasone 4mg qid is given as soon as a diagnosis of spinal cord compression is made or suspected. The features in Ahmed's history that make one suspect spinal cord compression are: his worsening back pain exacerbated by lying down, coughing and straining; his inability to stand up due to weakness

Selection 5: Prescribe an antidepressant

Answer:

The authors disagree.

In addition to the reasons behind Ahmed's request for a lethal injection, further discussion regarding Ahmed's depression needs to be addressed. If he has been depressed for more than two weeks, an antidepressant such as amitriptyline or a SSRI may be indicated. However in Ahmed's case his despair commenced a few days ago following consultation with his oncologist. At this stage supportive counselling may be sufficient in assisting him to overcome his distress.

Selection 6: Arrange a lumbar spine X-ray

Answer:
The authors disagree.

A plain X-ray of the spine is unhelpful in diagnosing spinal cord compression.

Selection 7: Arrange referral to a community based palliative care counselling service.

Answer:

The authors disagree.

Ahmed needs to be admitted to hospital for an MRI. If he has spinal cord compression he will be an inpatient for some time . It would be more appropriate to refer Ahmed to a community based palliative care service as part of his hospital discharge plan

Examination Findings:

On examination Ahmed is distressed when moving from a sitting position to lying down in bed. He is tender over his thoracic vertebrae at the level of T11 and T12. Flexion and extension of his back is reduced. Straight leg raising is limited to 70 bilaterally and is painful. Power of his hips and knees (flexion and extension) is assessed as being grade 4 out of 5 bilaterally, with decreased tone bilaterally. Knee jerks are present, but weak. Both plantar responses are downgoing.

Some subjective altered sensation is present but there are no objective sensory signs. Ahmed's bladder is not distended and his anal tone is normal. His gait is ataxic.

Question 2: Which of the following statements about spinal cord compression (SCC) are true?

Select one or more of the following

1. The most common initial symptom is pain.

2. Movement, coughing and straining, all exacerbate central back pain due to SCC.

3. Ataxia and sensory loss are invariably present.

4. The presence of autonomic dysfunction is not an important factor in terms of recovery of function.

5. SCC occurs in approximately 5% of patients with vertebral metastases.

6. The most common primary sites of patients with SCC are breast, prostate and lung.

7. Thoracic vertebrae are most commonly involved in SCC.

8. SCC does not require urgent management

9. 50% of ambulatory patients remain so after treatment.

Answers to Question 2

Selection 1. The most common initial symptom is pain.

Answer:

The authors agree.

The initial symptom in over 90% of patients with SCC, is pain.

Selection 2: Movement, coughing and straining, all exacerbate central back pain due to SCC.

Answer:

The authors agree.

Localised vertebral tenderness is also an associated sign.

Patients with pain from degenerative joint disease generally find their pain goes away when they lie down, whereas patients with nerve root irritation will experience pain on lying down.

Selection 3: Ataxia and sensory loss are invariably present.

Answer:

The authors disagree.

Ataxia and sensory loss are not necessarily present at the time of making a diagnosis of SCC. A history of progressive weakness is common

Selection 4: The presence of autonomic dysfunction is not an important factor in terms of recovery of function.

Answer:

The authors disagree.

The presence of autonomic dysfunction (eg. urinary retention, constipation, incontinence and impotence) is a poor prognostic factor in terms of likely recovery of function. It is important to assess the degree of autonomic dysfunction by palpating the abdomen for an enlarged bladder and assessing anal tone. The latter may be normal, reduced or absent in SCC.

Selection 5: SCC occurs in approximately 5% of patients with vertebral metastases.

Answer:

The authors disagree.

SCC occurs in approximately 20% of patients with vertebral metastases.

Selection 6: The most common primary sites of patients with SCC are breast, prostate and lung.

Answer:

The authors agree.

Other less common tumours include multiple myeloma, lymphoma and melanoma.

Selection 7: Thoracic vertebrae are most commonly involved in SCC.

Answer:

The authors agree.

Type of vertebrae involved in SCC	% of total cases
Thoracic	70
Lumbosacral	20
Cervical	10

NB: 5 — 15% of patients have multiple sites of compression, so it is important to image the whole spine. Anterior compression of vertebrae is most common.

Selection 8: SCC does not require urgent management.

Answer:

The authors disagree.

SCC is an emergency that requires rapid diagnosis and management. Without treatment, patients will develop paralysis and lose control of their bowel and bladder. A patient with SCC needs to be given steroid cover and then transported urgently to a hospital where both neurosurgical and radiotherapy facilities are available. The appropriate management option can then be determined by consulting a neurosurgeon and radiation oncologist.

Selection 9: 50% of ambulatory patients remain so after treatment.

Answer:

Patient mobility at diagnosis of SCC	Approx % of SCC patients able to walk after treatment
Ambulatory	80%
Non-ambulatory	30%
Paralysed	10% or less

Reference: Woodruff, R. Palliative Medicine. Symptomatic and supportive care for patients with advanced cancer and AIDS.

Third edition. Oxford University Press, 1999

Question 3: Name two other management options available for SCC in addition to oral steroids.

Author's answer:

Radiotherapy

Neurosurgery

Feedback

Radiotherapy is usually the treatment of first choice for SCC, in conjunction with oral steroids. It is particularly appropriate when compression is present at multiple levels. Back pain tends to resolve in 60-80% of patients as a result of having radiotherapy. The steroids reduce oedema, which is due to compression. Neurological signs need to be monitored carefully. If continued deterioration occurs, neurosurgery may be indicated, particularly if the patient is not terminally ill and/or does not have compression at multiple levels.

In general however the results of treatment with dexamethasone and radiotherapy, compared to dexamethasone, laminectomy and radiotherapy are equivalent from a neurological point of view.

A posterior laminectomy is the emergency treatment of choice for SCC patients with rapid neurological deterioration.

The contraindications to having a posterior laminectomy are listed below:

established paraplegia (> 72 hrs)

complete and rapid paralysis secondary to spinal cord infarction

restricted mobility

severely debilitated patients.

Reference: Woodruff, R. Palliative Medicine. Symptomatic and supportive care for patients with advanced cancer and AIDs. Third edition, Oxford University Press, 1999.

Further History

You inform Ahmed his back pain and weakness need to be urgently investigated in hospital. Ahmed informs you he wants to talk to Kate in private. During this time he airs his concerns about not wanting to be a burden tohis wife Fatima. He also tells Fatima he doesn't think all this fuss is necessary and it might be best if he just stays at home.

Fatima reassures Ahmed of her love for him. She stresses she is coping fine and wants everything possible to be done for him. She also reassures Ahmed he is not being a burden to her. As a result of this conversation, Ahmed agrees to be admitted to hospital. An urgent MRI scan confirms spinal cord compression at T11 and T12. Ahmed is given dexamethasone and a course of radiotherapy.

After being in a hospital, an hour's drive from home, for 11 days, Ahmed becomes increasingly despondent. He requests the radiotherapy be ceased due to a lack of response. Ahmed expresses a strong desire to return home to die in peace. He refuses to swallow any medication and keeps saying he just wants to go home.

A long discussion between Ahmed, Fatima and the radiation oncologist ensues. Fatima supports Ahmed's wish to return home. The radiation oncologist's registrar telephones shortly afterwards and informs you that Ahmed will be discharged the following day, a Friday. He adds the hospital staff 'don't think Ahmed will live through the weekend'.

Question 4

Select from the following the symptoms/behaviours which make you think a patient is terminally ill.

Select one or more of the following

1. profound weakness
2. essentially bed bound
3. drowsy for extended periods of time
4. disoriented with respect to time with a severely limited attention span
5. increasingly uninterested in food and fluids
6. finding it difficult to swallow medication

Answers

All options above are correct.

Even when it is obvious to health professionals that a patient is approaching death, it is important relatives be informed of this. Sometimes relatives do not realise how close death is and they may be upset about not having been warned.

*(Ref: Twycross R & Lichter I. The terminal phase in Oxford Textbook of Palliative Medicine, 2nd edition 1998).

Further History

You express your concern about being able to arrange appropriate home support services at such short notice. You also have a telephone conversation with Fatima who is at the hospital. She is worn out from travelling to and fro and wants to take Ahmed home.

You agree to support Ahmed and Faima and contact the community based palliative care team. You explain the situation and arrange for a palliative care assessment to be done on Friday once Ahmed has arrived home by ambulance. You ask Fatima to phone you and the palliative care team once Ahmed is home. After speaking to Fatima you also arrange for urgent home help and for the local minister to visit.

Caring for a dying person at home is a twenty four hour task which requires a broad range of skills. A general practitioner or trained Palliative Care nutse is in an ideal situation to manage a dying patient at home, and to coordinate their care. Members of a community based palliative care service can offer additional assistance. It is important to be able to work and liaise with other palliative care team members in an atmosphere of mutual respect and cooperation

The following are members of a palliative care team. If available they may all be able to assist in caring for Ahmed at home.

Palliative Care Nurse:

- assess symptom control
- provide information and support to patient and family (including advice about preventing pressure sores and what to expect as death approaches)
- attend to patient hygiene e.g. mouth care
- use complementary therapies (e.g. foot massage, therapeutic touch)
- discuss food and fluids according to needs
- set up syringe driver if required
- perform enemas, if patient is constipated
- stay with the family following death and involve them in the laying out process if they wish.

Counsellor:

Assesses the patient's carers and/or partners for risk of complicated grief. They can encourage these people to start expressing anticipatory grief. It may be helpful for the survivor to establish a relationship with a counsellor prior to a patient's death.

Volunteer

Provides respite and support for carers.

Further history

Ahmed arrives home by ambulance at 4pm on Friday. Fatima telephones you and you visit soon after. She discusses Ahmed's condition and also writes extensive notes in a home based medical record. This is an excellent vehicle for communication, if available. It can record important aspects of the patient's medical, social and psychological assessments and should be used by the general practitioner in order to ensure continuity of care is maintained. In this way, all members of the palliative care team have access to each other's notes.

You find Ahmed lying quietly in bed. He is pain free and not distressed. He tells you how happy he is to be home and how much it means to be able to look out the window and see his garden. Ahmed is still refusing to eat, drink or have any oral medications.

Fatima shows you the special underlay placed on the bed by the palliative care nurse, with the aim of preventing bed sores. Fatima also adds that she has been taught how to turn Ahmed in bed.

Fatima shows you the hospital discharge summary and informs you the hospital nurse taught her how to give Ahmed subcutaneous morphine injections through a butterfly which has been inserted into Ahmed's chest. The dose of morphine is 10 mg subcutaneously, 4 hourly, and 5 mg subcutaneously for break-through pain. Prior to this Ahmed had been on oral morphine.

You stay for almost an hour. Both Ahmed and Fatima tell you how reassured they are by your presence and support. You give Fatima your after hours phone number and advise you will visit the following day. You are pleased to meet Fatima's nephew who has agreed to share Ahmed's care.

By the time you leave, both Ahmed and Fatima are smiling. Ahmed requests a glass of milk. He also says he feels like eating again and would prefer to resume the morphine liquid he had been receiving in hospital up until the day before discharge. You go along with this request and convert the subcutaneous dose back to an oral dose. You also write him out a prn breakthrough dose of oral morphine as well.

Question 5

Fatima is keen to use non-pharmacological treatments to improve Ahmed's feelings of well being and to keep him calm and peaceful.

What would you suggest?

Answer

Burning lavender oil in the bedroom.

Playing soothing music that Ahmed likes.

Foot massage.

All of the above promote relaxation and reduce anxiety.

Further History

At review the following day, Fatima reports that Ahmed continues to be pain free.

You continue to give ongoing support to both Ahmed and Fatima. Despite being on Lactulose 30 mg bd, Ahmed is constipated. A rectal examination reveals hard faeces. An enema given by the palliative care nurse gives a satisfactory result.

A pastoral care worker from a palliative care team visits to offer spiritual support to Ahmed, Fatima and her nephew. A volunteer is also organised to give Fatima and her nephew some respite.

Ahmed's condition deteriorates over the next couple of days. He becomes profoundly weak, is bed bound and develops Cheyne-Stokes breathing

Cheyne-Stokes breathing

Cheyne-Stokes respiration is an abnormal pattern of breathing characterised by alternating periods of apnoea and deep, rapid breathing. The cycle begins with slow, shallow breaths that gradually increase in depth and rate and is then followed by a period of apnoea. The period of apnoea can last 5 to 30 seconds, then the cycle repeats every 45 seconds to 3 minutes.

Further History

All treatment is ceased except for morphine, which is adminstered by continuous subcutaneous infusion. You visit Ahmed twice daily. Ahmed is not expected to live through the day, however, to everyone's surprise, he improves after the session of therapeutic touch and starts breathing normally again.

When you review Ahmed the following day his symptoms are well controlled. He is able to drink fluids, is peaceful and pain free. He is able to carry out a conversation and is visited by many family members and friends, some of whom pray for him and read the Qu'ran to him. Other relatives visit him.

Ahmed remains peaceful and conscious for the next five days, during which time he is bedridden and slowly deteriorates. He is still able to respond with a smile when greeted just a few hours before his death. His conscious state deteriorates a short time before he dies. Fatima is with him when he dies.

Fatima telephones you and the palliative care community team soon after Ahmed's death.

Question 6

List the tasks you could undertake in this situation. Include any roles you would be comfortable taking on. Compare your list with author's and reflect on any differences in your approach to similar situations.

Answer

Confirm Ahmed's death.

Fill out the death certificate.

Give emotional support to Fatima, her nephew and any other family members who may be present (sit down with Fatima and accept any offers of hospitality).

Consider attending the funeral. Attending the funeral gives you an opportunity to farewell Ahmed and to grieve for him.

Debrief.

Debrief

The tasks involved in palliative care can often cause a variety of strong feelings to surface. It is not unusual for health professionals to experience grief as a result of caring for dying patients and their families. If these emotions are repressed, delayed or denied, this is likely to adversely affect the general practitioner's psychological health. Therefore it is preferable to air these feelings and share them with people who can be trusted, eg. friends, spouse, minister, colleagues — formally or informally. This process is known as debriefing. Another helpful approach is to write about one's feelings in a journal.

Further History

You call in on Fatima one week after Ahmed's death. She is pleased to see you as a visitor and lets you know that she is receiving support from many friends and neighbours. You suggest she comes to see you in a couple of weeks. Fatima makes it clear she doesn't like consulting doctors, but you think she will need grief counselling because of unresolved issues over her first husband's death. She thanks you for your care and concern.

Fatima does not attend the local doctor. However one month later, she requests you visit her at home.

You find her very distressed about a number of things and she thinks she is going to have a "nervous breakdown".

Fatima discusses her father. She compares the circumstances of his death, from stomach cancer, in a hospital, to Ahmed's death. She is very agitated and often uses Ahmed's name while speaking abouther father, and vice versa.

Question 6

What are some of the principles of bereavement counselling that are important in this situation?

One or more answers are correct

1. Allow Fatima time to tell her story
2. Give Fatima permission to grieve
3. Assess risk factors for complicated grief
4. Quickly offer Fatima a tissue after she starts crying

Answers

Selection 1: Allow Fatima time to tell her story

The authors agree.

A bereaved person needs to take time to tell their story in an unhurried environment.

Selection 2: Give Fatima permission to grieve

The authors agree.

When Ahmed was alive, Fatima was very strong and tended to deny her own needs. She didn't allow herself to express her anticipatory grief because she felt if she allowed herself to start crying she would have "fallen apart" and been unable to care for Ahmed. She may have also wanted to avoid upsetting Ahmed. Now that Ahmed is dead, Fatima needs to be given permission to grieve.

Selection 3: Assess risk factors for complicated grief

The authors agree.

It is important to address unresolved risk factors of grief. For Fatima these are:

the unresolved loss of her first husband's death from cancer and poor financial support. Other risk factors for complicated grief in general, are:

sudden, unexpected death, other concurrent stressors or crises, unresolved issues in relationship between deceased and survivor and poor social support.

Selection 4: Quickly offer Fatima a tissue after she starts crying

The authors disagree.

An important part of the healing process involves the bereaved person expressing their emotions. It is therefore important to be mindful of any factors that may inhibit this process, eg. blocking off tears by offering a tissue too quickly, or changing the topic quickly. Rushing in with a tissue too quickly can give a non-verbal message that says "dry your eyes and stop crying". It is also important to allow time for a bereaved person's tears to subside before expecting them to continue talking. Changing the topic in order to stop them from becoming too upset is not recommended either.

Question 7

How would you manage the situation with Fatima?

Select one or more of the following

1. Prescribe an antidepressant
2. Enquire about symptoms of depression
3. Enquire about past losses
4. Enquire about past psychiatric history
5. Refer Fatima to a grief counsellor
6. Reassure Fatima that her feelings will quickly resolve
7. Suggest that Fatima consider attending a "grief group"
8. Commence grief counselling

Answers

Selection 1: Prescribe an antidepressant

The authors disagree.

It is more important to encourage a grieving patient to express their emotions. Antidepressants may result in individuals not expressing their discomfort. It would only be appropriate to consider an antidepressant if the vegetative effects of depression (eg. loss of appetite, loss of concentration and difficulty sleeping) had been present for at least two weeks.

Selection 2: Enquire about symptoms of depression

The authors agree.

As mentioned previously , it is important to ascertain whether symptoms of depression are present, eg. loss of appetite, loss of concentration, difficulty sleeping and suicidal thoughts. The length of time the symptoms have been present, also needs to be ascertained.

Selection 3: Enquire about past losses

The authors agree.

Finding out how Fatima has coped with past losses is useful in assessing whether she may be at risk of complicated grief. It may also help in developing effective strategies or referring her to grief counselling sessions.

Selection 4: Enquire about past psychiatric history

The authors agree.

Ascertaining whether Fatima has had a past psychiatric history is useful in assessing whether she may be at risk of developing complicated grief or a recurrence of her psychiatric illness.

Selection 5: Refer Fatima to a grief counsellor

The authors agree.

Fatima needs grief counselling and has stated and demonstrated she is reluctant to visit doctors. She may be more willing to have counselling from a coomunity based organisation. Sometimes grief counselling is available from a member of the community based palliative care service, eg. a specialist bereavement counsellor. Ideally this counsellor will have already established a relationship with the carer before their loved one has died, although this is not often the case. Also, some GPs do not feel comfortable participating in grief counselling. If so, it is suggested these patients are referred to someone they are comfortable with.

Selection 6: Reassure Fatima that her feelings will quickly resolve

The authors disagree.

The process of working through grief may take a long time. Fatima can be reassured that she won't always feel like she does.

Selection 7: Suggest that Fatima consider attending a "grief group"

The authors agree.

Although Fatima may not feel ready or willing to attend such a group, some patients find they gain a lot of comfort and mutual support from sharing their experiences of grief with others. It is worth pointing out the benefits of attending such a support group, for newly bereaved people.

Selection 8: Commence grief counselling

The authors agree.

You are in an ideal situation to offer grief counselling to their patients. If you feel comfortable in this role, then it is highly recommended you make yourself available to do such counselling. Other general practitioners would feel more comfortable referring cases of complicated grief to a psychiatrist or bereavement counsellor.

Question 8

Which of the following statements are true about grief?

1. There are three main tasks of mourning, according to Professor Beverley Raphael. These are:

To accept the reality of the loss.

To adjust to life without the dead person.

To withdraw emotional energy from the dead person and reinvest it into other relationships.

2. Grieving people tend to go through a process of grief that starts with shock and ends in a feeling that life is worth living.

3. Grieving people go through a process in which they experience the following emotions in the following order:

Denial - Anger -Bargaining - Depression - Acceptance

Answers

Selection 1

The authors disagree.

According to Professor Beverley Raphael*, there are four main tasks of mourning. These are:

To accept the reality of the loss.

To experience the pain of mourning.

To adjust to life without the dead person.

To withdraw emotional energy from the dead person and invest it in other relationships.

*Raphael B, The anatomy of bereavement. Hutchinson, London 1984.

Selection 2

The authors disagree.

Dr Elisabeth Kubler-Ross* has described the process of grief under the headings of denial, anger, bargaining, depression and acceptance.

However, grieving people often jump from one emotion to another rather than experiencing it as a smooth progression from one stage to the next. The order of experiencing emotions may also be different.

*Kubler-Ross, E. On death and dying. Tavistock Publications, London 1969.

Selection 3

The authors disagree.

Dr Elisabeth Kubler-Ross* has described the process of grief under the headings of denial, anger, bargaining, depression and acceptance.

However, grieving people often jump from one emotion to another rather than experiencing it as a smooth progression from one stage to the next. The order of experiencing emotions may also be different.

*Kubler-Ross, E. On death and dying. Tavistock Publications, London 1969.

The Final Outcome

Fatima agrees to see you for support and grief counselling for five sessions over a period of several months.

Although she misses Ahmed, she likes living by herself and continues to receive plenty of support from her local community. She resumes gardening and starts thinking about doing community work herself as a volunteer.

Middle East Journal of Nursing
medi+WORLD International 2018