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USING COMPLEMENTARY AND ALTERNATIVE THERAPY AMONG CANCER PATIENT: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Access to and advice on Complementary and Alternative Medicine (CAT) are uncommon within Egyptian conventional cancer care and little is known about cancer patients' own use of CAT. The aim of this study was to explore using complementary and alternative therapy among Egyptian Cancer Patient and their experiences and preferences. Methods: Questionnaires were distributed consecutively to 1297 cancer patients at Tanta Oncology hospital's out-patient & inpatient and social media. The response rate was 58% (n = 755). Descriptive statistics were used to analyze the survey data. A logistic regression model was used to investigate the association between CAT use and gender, age and level of education. Open-ended responses were analyzed, using qualitative content analysis. **Results:** Lifetime CAT use was reported by 34% (n = 256), and 26% (n = 198) used CAT after cancer diagnosis. Being female, younger and having higher education predicted CAT use. Most commonly used methods were natural products including vitamins and minerals and relaxation. Main reasons for CAT use were improvement of physical, general and emotional wellbeing and increasing the body's ability to fight cancer. Satisfaction with CAT usage was generally high. Reported adverse effects were few and mild; 54% of users spent < 50 Egyptian pound a month on CAT. One third had discussed their CAT use with cancer care providers. More than half of all participants thought that cancer care providers should be able to discuss (58%) and to consider (54%) use of CAT modalities in cancer care. Conclusions: Despite limited access and advice within conventional cancer care, one fourth of Egyptian cancer patients use CAT. The insufficient patient-provider dialogue diverges with most patients' wish for professional guidance in their decisions and integration of CAT modalities in conventional cancer care. Concurrent and multimodal CAT use implies challenges and possibilities for cancer care that need to be considered.

KEYWORDS: Complementary and Alternative Medicine (CAT), logistic regression model.

BACKGROUND

Complementary and Alternative Therapy (CAT) is a broad set of non-mainstream practices including use of natural products, mind-body therapies and entire medical systems. [1] Use among cancer patients has increased in the last decades. [2] National and regional heterogeneity. gender, age, education and type of tumor appear to influence usage patterns and frequency. [2,3,4] Research on both effectiveness and risks of specific CAT modalities for cancer patients accumulates^[5] and attempts to establish evidence-based clinical guidelines are made^[6] and have recently been endorsed by the American Society of Clinical Oncology. [7] Open communication between patients and cancer care providers (beneath referred to as providers) has been valued essential to meet patients' needs and to improve understanding regarding direct risks as well as to prevent indirect risks. [8] The authors of several studies [9,10,11,12] highlight the need of an improved dialogue concerning CAT. Leading comprehensive cancer centers^[13] provide the concept of integrative oncology^[14] as a patientcentered health care model to meet patients' preferences, to ensure their safety and to optimize clinical outcomes. Other authorities have established research centers and scientific information services about CAT. [1,19]

Previous studies on Egyptian cancer patients' CAT use have mainly focused on natural products^[20] and specific groups of patients^[10,20] and indicate similar usage frequency as other high-income countries. Research on Egyptian professionals' perceptions of CAT indicate uncertainty about evidence, indications, contraindications and skepticism about high costs.^[21,22,23]

Practice of evidence-based medicine requires integrating individual clinical expertise, patient values and circumstances with the best available external clinical evidence from systematic research. To understand patient values and circumstances in relation to CAT it is crucial to study usage across different countries and cultures. This cross-sectional study builds on previous

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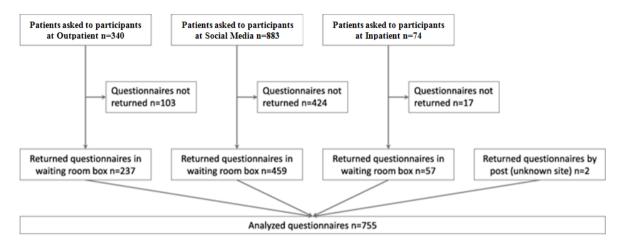
surveys to advance the view of cancer patients' CAT use in general, focusing on Egyptian cancer patients' experiences and preferences.

METHODS

Participants and inclusion

Data were collected from the three places; outpatients, inpatient (Fig. 1) at Oncology Hospital in Tanta with

14,614 patients during 2015 covering the region of Al-Gharbia with 4,751,865 million of 10 million inhabitants in Egypt and from social media cancer patients. We chose social media patients to touch different categories of cancer patients because out & in patient clinics attract low and moderate socioeconomic state patients while social media patients have more diversity.



Flow chart of data inclusion

Inclusion criteria for study participants were re-visits to oncologist or nurse implying active oncological treatment (radiotherapy, chemotherapy and other medical cancer therapies) or follow-up; curative or palliative stage of the disease; solid tumor (breast cancer, gynecological - urogenital -, or gastrointestinal cancer, head-neck cancer, lung cancer, skin cancer, thyroid cancer, sarcoma, tumors with unknown primary or brain tumor). Exclusion criteria were first-time visits since we

wanted to explore CAT use *after* cancer diagnosis, and treatment visits for chemotherapy and radiotherapy in order to avoid duplicate answers.

Data collection

The study employed a cross-sectional design. Participants were asked to fill in a questionnaire with 19 questions including yes/no and multiple-choice responses as well as free text options (Table 1).

Table 1: Measures derived from data collection with questionnaire.

Measures	Q No	Question	Response options	Additional free text option
	1	Age	Open	
	2	Gender	Man/woman	
	3	Cancer site	Open	
Patient	4	Highest level of education	Multiple choice	
characteristics CAM use	5	Use of complementary or alternative medicine at any point in life	Yes/No	
	7	Use of specific CAT therapy before and/or after cancer diagnosis, and/or in present time	Multiple choice ^a	X
	8	When was CAT initiated?	Open	
Adverse effects	11	Adverse effects	Yes/No ^b	X
	15	Communication about CAT with conventional health care providers	Yes/No	
Dialogue about	15a	If communication, what was it about?	Open	
CAM	15b	If communication, were you satisfied with the dialogue?	Yes/No	X
	15c	If not, why did you not communicate about CAT?	Open	
Sources of	16	Source of information about CAT	Multiple choice	X
information	18	Desired information pathway regarding CAT	Multiple choice	X
	9	Reason for CAT use	Multiple choice	X
Reasons	6	Main reason(s) for not using complementary and alternative medicine	Multiple choice	X

	10	Perceived benefit of CAT therapy	Multiple choice ^c	X
Benefits,	14	Satisfaction with CAT use after cancer diagnosis	Multiple choice	X
satisfaction,	12	Expenditure on CAT methods per month	Multiple choice	
costs	13	Perception whether CAT use was worth the money	Yes/No	X
Role of cancer care in relation	17	Conventional health care providers should be able to answer questions about CAT	Multiple choice	
to CAM	19	View on the role of conventional health care in relation to providing some CAT	Yes/No	X

^a List of 27 specific methods, space for additional therapies and specifications e.g. on type of herbal remedy or vitamin/mineral; ^bFree text option for specification of therapy and adverse effect; ^c Eight choices including no benefit at all.

Ouestionnaire content

The questionnaire previously used by Molassiotis et al.^[3] was translated to Arabic and further adapted by the research team to suit the purpose of the present study and the local context. We excluded 8 items on background questions (income, ethnic group, religious beliefs and previous cancer treatment), 2 items regarding frequency of CAT use and 4 items concerning sick-leave, hospitalization and other health care visits. Moreover, 6 items on CAT use were merged into 1 item. The questionnaire ultimately contained 19 questions on demography, CAT use, reasons, used methods and details on experiences of and views on CAT (Table 1).

Data collection procedures

During one week (September 2014), all patients with appointments for cancer treatment or follow-up were informed by (written information about the study, voluntary participation and confidentiality). Patients willing to participate, completed the anonymous questionnaire in the waiting room and left it into a designated post box. There was no opportunity offered to complete the questionnaire at home for the participants at out-patient & inpatient clinics only. Social media patients can fill it online.

Statistics and data analysis

Data was summarized by descriptive statistics (frequencies and percentages). To investigate factors possibly associated with CAT use, Spearman correlation coefficients were calculated for CAT use versus gender, age and level of education and possible associations between these variables were explored with a logistic regression model. All calculations were done in STATA®.

Participants' free-text responses analyzed were descriptively question-by-question according principles of qualitative manifest content analysis by the two co-assistant researchers independently [25, 26]. The length of the free-text responses varied from one word to a few sentences. After reading all responses and compiling them into meaning units, the two co-assistant researchers agreed upon a coding scheme for each response section. The codes within each section were then compared and contrasted and sorted into categories. categories including example statements representing each category are presented in Table 2. These results were used for better understanding of quantitative data and as control whether there were missing options in the multiple-choice questions.

Table 2: Categorization of free-text responses with example statements.

Question	Category	Examples of statements within category	
Q9. Reasons for CAM use	Specification of improved physical well-being $(n = 12)$		
(n = 13, N = 198)	Refraining conventional treatment $(n=1)$	"Did not want conventional treatment because I didn't want any more poison in my body."	
	Specification of physical and emotional well-being $(n = 14)$	"Less pain and better mobility."	
Q10. Benefits of CAM $(n = 31, N = 198)$	Some CAM of value, some not (n = 2)	"Have experienced many side-effects from the antiestrogen treatment but my sexual life has not been affected, my mucous membranes are not dry. Because of the primrose oil? Not of any use: The acupuncture that even hurt sometimes."	
	I do not know (yet) (n = 15)	"Difficult to know what it would have been like without [CAM]. If it had any effect or not."	
Q13. Was CAM worth the	CAM use significant in life (n = 15)	"I got a new life. Even if I would die tomorrow, it would have been worth it."	
money? $(n = 54, N = 198)$	Improvement of psychological, physical	"Yoga makes me feel at peace and improves strength and	
	or spiritual well-being (n = 24)	flexibility and gives me a sense of having power."	
	Some CAM of value, some not $(n = 2)$	"The chiropractic practice helped me for some time with	

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		my wryneck, but the antioxidants were not worth the money."	
	Wish for economical support for CAM	"My economy cannot take anti-cancer foods in the long	
	use (n = 6)	run."	
	I do not know (yet) $(n = 7)$	"Too early to evaluate."	
	Specification of effect (n = 12)	"Did not notice the benefit before I stopped taking this	
Q14. Satisfaction with	` '	mistletoe extract. Then I started again."	
CAM use $(n = 31, N = 198)$	I don't know (yet) (n = 14) CAM use not in association to cancer	"Difficult to say as a lay person."	
	(n=5)	"I have not used CAM for cancer."	
Q15a. Topic of discussion	Use of specific method was encouraged (n = 12)	"The doctor encouraged me to use acupuncture."	
with cancer care	Ok to use $(n = 10)$	"The doctor thought it was totally ok."	
professionals $(n = 49, N = 79)$	Patient asked to take own responsibility for use $(n = 10)$	"Not his field but did not discourage me [from CAM use]."	
(12,14 12)	Recommendation to refrain usage (inclusive of interaction) ($n = 17$)	"The doctor said no to everything except what the Oncology department offered."	
	Specification of discussion about	"Got an answer to my vitamin D in my blood. In the end, I	
	specific method (n = 6)	stopped taking vitamin D since the test showed too much."	
		"Without nuance, uninformed and non-empathic. You	
		don't have to recommend complementary methods if you	
Q15b. If discussion, were	Lack of knowledge about CAM among	are so afraid of them before time has passed and additional	
you satisfied? $(n = 27,$	health care providers (n = 7)	20 research results have proven benefits. But you could	
N = 79		report about current research and where one can find	
		research reports. I have been asking for this but have not gotten any help."	
		"There is research in the rest of the western world that is	
	Wish for open attitude and competent	genuine. // Swedish doctors/nurses would benefit from	
	answers $(n = 14)$	being open to alternatives."	
		"Everyone knows about the lack of knowledge [about	
		CAM] among doctors and their out-of-date attitudes	
	Expected negative answer $(n = 18)$	regarding alternatives that do not constitute medicines or	
Q15c. Why not discussed?		surgery. Unnecessary when one needs their support and not	
(n = 77, N = 119)		their irritation and skeptical attitude."	
	No reason to discuss $(n = 44)$	"The staff has the attitude: If you think it helps, then"	
	Nobody asked $(n = 8)$	"I have not gotten the question."	
	Lack of time or continuity $(n = 7)$	"Lack of time and lack of interest [from providers]." "Big interest in my whole life."	
Q16. Sources of	Own experience and interest (n = 15)	· ·	
information about CAM	Literature, lectures, courses, patient organizations $(n = 9)$	"Books like: Anti-cancer, Are Waerland, Maesegården."	
(n = 26, N = 198)	Other therapists $(n = 2)$	"My personal trainer."	
	Important with evidence, competence	"Good with holistic perspectives and sound scientific view	
	and quality (n = 42)	on these methods. Otherwise one easily goes to quacks."	
Q19. View on the role of	Suggestion of method and/or indication	"Important to offer all help that supports the fighting of	
conventional health care in	(n=34)	cancer, especially considering all difficult hospital visits."	
relation to providing some	As provider of information on CAM	"Tell me what there is, and I can make the decision	
CAM $(n = 89, N = 198)$	(n = 10)	myself."	
	Wish for treatment diversity $(n = 3)$	"Right now, there is only one alternative. There needs to be	
	transpared N = number of responses to mi	options."	

n = number of free-text responses, N = number of responses to multiple choice/yes/no question

Measures

Participants' characteristics and CAT use were assessed by question (Q) 1–8, adverse effects by Q11, dialogue about CAT and sources of information by Q15, 16 and 18; reasons for CAT use, perceived benefits, satisfaction and monthly costs by Q9, 10, 12–14 and the role of cancer care in relation to CAT by Q17 and 19 (see Table 1).

RESULTS

Participants' characteristics and CAT use

Out of 1297 eligible patients, 58% (n = 755) returned the questionnaires. Content and response options are shown in Table 1, patient characteristics in Table 3.

Table 3: Patient characteristics.

Patient characteristics	Patients	CAM user	No CAM user	Spearman's correlation	n rolus	
Patient characteristics	% (n)	% (n)	% (n)	coefficient, rs	<i>p</i> -value	
Age in years				-0.25^{a}	< 0.01	
< 30	2 (12)	2 (4)	1 (8)			
30–49	17 (130)	30 (59)	13 (71)			
50–69	46 (344)	46 (91)	45 (253)			
> 70	31 (234)	16 (32)	36 (202)			
Unknown	5 (35)	6 (12)	4 (23)			
Total	101 (755)	100 (198)	100 (557)			
Sex				0.22 ^b	< 0.01	
Women	65 (490)	81.5 (161)	59.5 (329)			
Men	35 (265)	18.5 (37)	40.5 (228)			
Total	100 (755)	100 (198)	100 (557)			
Diagnosis						
Breast cancer	38 (285)	51 (101)	33 (184)			
Urogenital cancer	18 (138)	8 (16)	22 (122)			
Gastrointestinal cancer	14 (103)	9 (18)	15 (85)			
Gynecological cancer	12 (92)	16 (31)	11 (61)			
Head, neck, lung or skin cancer	12 (92)	11 (21)	13 (71)			
Sarcoma	0(2)	1(1)	0(1)			
Unknown	6 (43)	5 (10)	6 (33)			
Total	100 (755)	100 (198)	100 (557)			
Highest education				0.14 ^c	< 0.01	
Elementary school	18 (137)	8 (16)	22 (121)			
High school	31 (233)	31 (62)	31 (171)			
College/University	49 (368)	57 (112)	46 (256)			
Unknown	2 (17)	4 (8)	2 (9)			
Total	100 (755)	100 (198)	100 (557)			

^ars calculated using age as a continuous variable; ^brs calculated with a positive correlation for women; ^crs calculated using 4 categories with increased value for higher highest education.

We found no statistically significant gender difference between eligible patients (65% women, 35% men) and participants (65% women, 35% men).

Use of CAT over lifetime was reported by 34% (n = 256) of the participants and 26% (n = 198) had used CAT after their cancer diagnosis (beneath referred to as CAT users). Onset of CAT use was specified by 77/198 CAT users; the majority stated either a time correlation to

cancer diagnosis or to cancer treatment. We found that 31 different CAT modalities were used by 198 patients after cancer diagnosis. Most frequently used CAT modalities were vitamins and minerals, natural products and relaxation (Table 4). Each modality may in itself represent many different variations, such as different types of mindfulness or yoga. "Vitamins and minerals" for example, implied usage of 22 different substances and the option "natural products" 32 different products.

 $\begin{tabular}{l} \textbf{Table 4: Distribution of used CAT modalities. Categories according to National Center for Complementary and Integrative Health.} \end{tabular}$

Used CAM modalities	% (n)
Category Natural products	
Vitamins, minerals	10.1 (66)
Natural products	9.3 (61)
Injection of mistletoe preparations	1.8 (12)
Aromatherapy	0.8 (5)
Category Mind and Body Practices	
Relaxation	9.0 (59)
Massage	8.7 (57)
Yoga	6.9 (45)
Meditation	6.7 (44)
Acupuncture	6.1 (40)
Mindfulness	5.3 (35)
Prayer	5.3 (35)

Naprapathy, chiropractic	4.0 (26)
Tai chi, Qigong	3.7 (24)
Spiritual guidance, healing	2.6 (17)
Supporting group(s)	1.7 (11)
Art therapy	1.4 (9)
Zone therapy	0.9 (6)
Rosen Method Bodywork	0.3 (2)
Shiatsu	0.3 (2)
Hypnosis	0.2(1)
Feldenkrais method	0.2 (1)
Hyperthermia	0.2(1)
Acupressure	0.2(1)
Eurythmy therapy	0.2(1)
Category Other Complementary Health Approaches	
Changes in diet	7.9 (52)
Anthroposophic medicine	2.4 (16)
Homeopathy	1.4 (9)
Energy medicine	0.8 (5)
Traditional Chinese Medicine	0.8 (5)
Ayurveda	0.6 (4)
Laser therapy	0.6 (4)
Total used modalities	100 (656)

We found statistically significant correlations between use of CAT and being female (rs = 0.22, P < 0.01), younger (rs = 0.25, P < 0.01) and having a higher education (rs = 0.14, P < 0.01). This was confirmed by logistic regression model with gender, age and level of education as predictors and usage of CAT as a dependent variable (p < 0.01). The model explains the variation of CAT users vs. No CAT users with 6%.

Adverse effects

A total of 5.6% (n = 9) CAT users reported 11 adverse effects related to a CAT modality. Five reports related to gastrointestinal symptoms from mung bean sprout juice, iron, apricot pits, low-carb-high-fat diet during chemotherapy and one unknown remedy, respectively. Fever and shivering were reported from mistletoe, cough and morning fatigue from cannabis and pain from acupuncture needles. Two reports regarded undesirable effects of more reflective character, since detoxification from spirulina and possible toxification from intake of pesticides via fruits and vegetables was mentioned as adverse effects without reference to concrete symptoms. Finally, one report concerned an x-ray finding of a kidney stone and a reflection on overconsumption of spinach as possible cause.

Dialogue about CAT and sources of information

Among CAM users, 33% (n = 66/198) had discussed CAT with their physician or nurse compared with 2% (n = 13/557) among No CAT users.

Responses regarding the providers' (physician or nurse) reactions to CAT related questions, ranged from approval or advice that CAT use was one's own responsibility to recommendation to refrain use. A general concern among participants was that they thought providers ought to be more open and

knowledgeable about CAT (see Table 2 Q15b). One participant stated: "There is research in the rest of the western world that is genuine /.../ Swedish doctors/nurses would benefit from being open to alternatives.". Participants' main reasons for not discussing CAT with their providers included expectation of negative attitudes, lack of time or continuity, absence of reason to bring up the topic and simply because "Nobody asked".

The most common sources of information about CAT among both CAT users and No CAT users were media (n=214), family or friends (n=154) and internet (n=118). CAT therapists were less common as information sources (n=35) and conventional care least common (n=26). Other sources (n=63) involved own experiences and interests, literature, lectures, courses, patient organizations and other therapists.

Most patients reported that they preferred receiving information on CAT during personal counselling with a skilled person (n = 354). Written information, e.g. webpages or patient brochures (n = 245) and lectures (n = 93) were other options, while relatively few (n = 42) wanted to chat online.

Reasons for CAT use, perceived benefits, satisfaction and monthly costs

The most commonly reported reasons for CAT use were to improve physical and general well-being (Fig. 2). The majority of free-text responses were specifications of the pre-listed options in the multiple-choice question (see Table 2 Q9). For example, one woman specified: "To counteract strong hot flushes." Only one response could be attributed to a reason for CAT use beyond the given options, i.e. because of declining conventional oncological treatment.

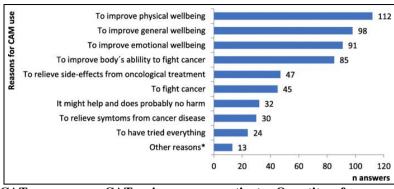


Fig.-2: Reasons for CAT use among CAT using cancer patients. Quantity of answers per reason. * "other reasons" from free text option (see Table 2 Q9).

The explanations given not to use CAT were mainly satisfaction with received conventional cancer care, never having thought about CAT use or disbelieve in methods lacking scientific prove. Less frequent reported reasons were economy or discouraging advice from friends, family or cancer care.

Perceived benefits of CAT were mainly improved physical and emotional well-being (Fig. 3). The free-text responses related to perceived benefits did not diverge from the pre-listed options but were rather specifications of experiences in relation to CAT use, perceived effects or lack of effects, and thoughts regarding the difficulty of evaluating effect (see Table 2 Q10). For example, one woman stated: "Have experienced many side-effects from the antioestrogen treatment but my sexual life has not been affected, my mucous membranes are not dry. Because of the primrose oil? Not of any use: The acupuncture that even hurt sometimes."

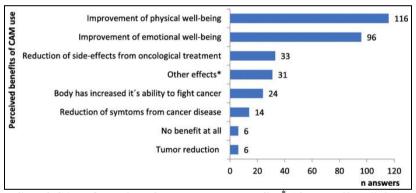


Fig.-3: Perceived benefits of CAT. Quantity of answers per benefit. "Other effects" from free text option (see Table 2 Q10).

Most participants (87%, n=113) who reported their grade of satisfaction (n = 130) were very (45%, n = 58) or quite (42%, n = 55) satisfied with their CAM use; 12% (n = 15) were a bit satisfied and 2% (n = 2) not satisfied at all. More than half of the patients reported spending \leq 50 L.E monthly while 3% spent >500 L.E. Over 90% of the patients reported that they considered their CAT

therapies worth the cost (Table 5). In the free text responses related to expenses, several patients highlighted the value of CAT for life in general (see Table 2, Q13). One participant wrote: "I got a new life. Even if I would die tomorrow, it would have been worth it".

Table 5: Monthly costs for CAM and reported value.

Monthly costs L.E ^a	CAT user % (n)	Worth the money % (n)	Not worth the money % (n)	Missing answer % (n)
0	20 (39)	_	_	_
1–50	34 (67)	88 (59)	0 (0)	12 (8)
51-100	16 (31)	94 (29)	0 (0)	6 (2)
101-500	10 (19)	74 (14)	11 (2)	16 (3)
501-1000	2 (3)	100 (3)	0 (0)	0 (0)
> 1000	1 (1)	100 (1)	0 (0)	0 (0)
Unknown	19 (38)	_	_	_
1->1000	61 (121)	88 (106)	2 (2)	11 (13)

a EGP

The role of cancer care in relation to CAT

Over two thirds of the CAT users and nearly half of No CAT users expressed that providers should be able to answer questions about CAT (Table 6) and that CAT therapies should be offered in the regular oncology settings (Table 7). The option to leave additional responses was used by 89 out of 198 CAT users: they

addressed the importance of evidence (n = 42), competence and quality of CAT modalities that they thought should be included in oncological care, they suggested specific methods or indications, expressed the wish that providers should at least offer information on CAT modalities and specified a wish for treatment diversity.

Table 6: Should providers be able to inform?

Should cancer care provider be able to inform about CAM?	Patients % (n)	CAM user % (n)	No CAM user % (n)
Should be able to inform	53 (403)	67 (132)	49 (271)
Need not be able to inform	4 (30)	2 (4)	5 (26)
No opinion or missing answer	43 (322)	31 (62)	47 (260)
Total	100 (755)	100 (198)	100 (557)

Table 7: Should CAT be offered within conventional cancer care?

Should certain CAT modalities be offered?	Patients % (n)	CAM user % (n)	No CAM user % (n)
Should be offered	54 (411)	71 (141)	48 (270)
Should not be offered	23 (177)	15 (29)	27 (148)
Missing answer	22 (167)	14 (28)	25 (139)
Total	100 (755)	100 (198)	100 (557)

DISCUSSION

This study describes CAT use and related experiences among Egyptians patients with solid tumors in both curative and palliative stage. One third (34%) of participants had used CAT at some point in their life and 26% after cancer diagnosis. This is in line with previous studies, e.g. a European study where CAT use was reported by 36%, [3] without distinction between use before or after cancer diagnosis. The similarity to our findings is surprising as access to and advice on CAT modalities are generally low within cancer care in Egypt, due to Egyptian regulations requiring health personnel to practice in accordance with "science and experiential knowledge". [27,28] Since patients in this study visited an oncological department, CAT seems to be mainly used complementary and not alternatively to conventional therapy. This also corresponds to participants' free-text responses where they specify reasons for and benefits from CAT use.

In line with international^[3,29,30] and other Scandinavian surveys, we found statistically significant relationships between CAT use and being female, younger and higher educated. These results may suggest high health literacy among CAT users and a gender aspect of unmet needs in conventional care.

In agreement with previous results^[3,31] we found that patients used and combined a diversity of CAT modalities. Natural products and mind-body therapies were most popular. This concurrent and multimodal use implies an immense challenge for research and practice in regard to interactions,^[32] efficacy and educational needs among patients as well as providers in a pluralistic context.^[33]

In our study, 5.6% of CAT users reported mild and transient adverse effects (mostly gastrointestinal discomfort) from a CAT modality, which was mainly related to intake of natural products, as shown earlier. [3,9,34] Participants' detailed specifications related to their experiences of CAT use as well as previous results on patients' concerns about risks for interactions^[35] indicate that many CAT users pay close attention to both positive and negative consequences of their CAT use. Thus, patients seem to be a potential and possibly underestimated resource for monitoring of adverse effects and effectiveness, as also acknowledged by the introduction of PROM/PREM in evaluating clinical trials. Therefore, an open and trustful dialogue between patients and providers is fundamental. However, in our study only 2% of No CAT users and 33% of CAT users had discussed CAT modalities with their provider, i.e. less than in recent Scandinavian literature. [9,10,34] The results from these previous studies indicate that around 50% of patients have a dialogue about CAT. Consequently, up to 67% of CAT use in our study may be unknown to providers representing both potential risks and undiscovered possibilities. Since CAT users were more likely to have discussed CAT compared to No CAT users, this dialogue was usually patient initiated, suggesting a threat to patient safety. For example, it has been shown previously that physicians who are perceived to be poorly informed or negative about CAT induce safety concerns in terms of e.g. potential undiscovered interactions as well as patient anxiety. [35]

Two thirds (67%) of CAT users and 49% of No CAT users (Table 6) thought that providers should have enough knowledge to be able to answer questions on CAT; which has been shown earlier. However, conventional health care was the least common source of information about CAT modalities while media, family

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or friends and internet were most commonly used; as previously reported^[31,34] and highlighting the need for quality assured information. Our findings are not surprising since Egyptian health care professionals still report lack of knowledge about CAT. [11,21,36,37,38] Better knowledge is known to increase dialogue. [21,22,23]

The main reasons for CAT use were to improve wellbeing and to increase the body's ability to fight cancer. Benefits were reported as being mostly physical and emotional. Both reasons for use and perceived benefits were often multifaceted, e.g. a single CAT modality was used and perceived efficacious both for improving emotional well-being and reducing adverse effects of conventional treatment. Notably, fighting cancer was rarely given as a reason for CAT use. These results correspond to earlier research indicating complex motives for CAT use, [39,40,41,42,43] shifting motives over time^[34,44] and benefits not always related to initial reasons for use. [3,8,30] Also, in line with previous findings, [3] patients in this study reported high satisfaction with CAT (87%) and the majority of users considered CAT being worth the money (91% of CAT users). Moreover, 71% of CAT users and 48% of No CAM users considered that CAT modalities should be offered within conventional cancer care and participants stressed the importance of scientific evidence, competence and quality of CAT. While patients' satisfaction with care - conventional or CAT - is multifaceted and clearly needs to be considered together with other aspects of evidence, as also patients argue in their responses, the high satisfaction rates among CAT users found here needs to be considered by decision makers in cancer care.

Strengths of this study include the cross-sectional design with three different data collection sites with different categories of participants specific through social media and the large sample size. These factors help ensure representativity for cancer patients with solid tumors in Egypt, although the results may not be fully transferable to more rural areas. The questionnaires were completed anonymously, and responses could not be linked to electronic health records or sociodemographic variables; thus, participants' diagnoses and socio-demographics are exclusively self-reported. Self-selection bias potentially attracting CAT users to participate to a larger extent than No CAT users is however unlikely since gender proportions were similar in visits to the clinic and responses to the questionnaire. If CAT users had been more likely to respond to the questionnaire, there would be an overrepresentation of women among responders since female patients represented 80% of CAT users in our material.

Strengths with the questionnaire, and that space was given for additional free-text responses. The recruitment of participants at outpatient & inpatient clinic of Tanta Oncology hospital and through social media might explain somewhat lower CAT use compared with

previous studies. Terminally ill patients were not represented and in general, participants might have been reluctant to admit CAT use while waiting for conventional oncological care. The response rate of 58% could be seen as a limitation of the study and a higher response rate would have been desirable, however, it is in line with previously published CAM surveys. [45]

CONCLUSION

Less than one fourth of Egyptian cancer patients use CAT, are highly satisfied with this use, generally have reasonable expectations and are alert to the consequences. Therefore, our results point to an urgency of research on CAT and an informed professional practice to ensure patient safety and satisfaction. Cancer care professionals need to be able to discuss CAT based on the three principles of evidence-based medicine (patients' values, professional experience, current research). Egyptian cancer care needs a strategy for research and education about CAT to integrate CAT modalities with shown beneficial value for patients and to avoid possibly harmful CAT. The concept of integrative oncology^[14] may provide a professional solution both regarding providers' and patients' needs.

ABBREVIATION

CAT: Complementary and Alternative Therapy *Q:* Question

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